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### ABSTRACT

This resource guide, the first of three volumes, lays out the fundamentals of outcome measurements for assistive technology. It includes the whys and hows of gathering data so that assistive technology practitioners can integrate outcomes measurement activities in their daily practice. Chapters include: (1) "Concepts and Rationale for Accountability in Assistive Technology" (Frank DeRuyter), which addresses scope of assistive technology practice and need for quality and assistive technology stakeholders of quality; (2) "Accountability in Assistive Technology" (Roger O. Smith), which discusses the hierarchy in the complexity of assistive technology outcomes, major domains of outcome, types of performance, the taxonomy of outcomes, and outcome measures; (3) "Program Evaluation" (Jan Galvin); (4) "Characteristics of a Meaningful Outcome Assessment" (Marcia J. Scherer); and (5) "Where Are We Headed with Assistive Technology Outcomes?" (Roger O. Smith and Marcia J. Scherer), which addresses issues in the measurement of assistive technology outcomes and selecting the outcomes to measure. An annotated bibliography is provided on assistive technology and outcomes assessment that contains 40 resources. (Each chapter includes references.) (CR)

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### VOLUME I RESNA RESOURCE GUIDE FOR

### ASSISTIVE TECHNOLOGY OUTCOMES: MEASUREMENT TOOLS

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--- Lucy U. Vitaliti, Ph.D. Project Director

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### VOLUME I -- RESNA RESOURCE GUIDE FOR ASSISTIVE TECHNOLOGY OUTCOMES: MEASUREMENT TOOLS

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### VOLUME I -- RESNA RESOURCE GUIDE FOR ASSISTIVE TECHNOLOGY OUTCOMES: MEASUREMENT TOOLS

### **INTRODUCTION**

This document is the first of the three volume set of the RESNA Guide for Assistive Technology Outcomes. The volumes are as follows:

VOLUME I: RESNA RESOURCE GUIDE FOR ASSISTIVE TECHNOLOGY OUTCOMES: MEASUREMENT TOOLS

This is an easy-to-read text that lays out the fundamentals of outcomes measurement. It includes the whys and hows of gathering data so an A.T. practitioner can integrate outcomes measurement activities in their daily practice.

VOLUME II: RESNA RESOURCE GUIDE FOR ASSISTIVE TECHNOLOGY OUTCOMES: ASSESSMENT INSTRUMENTS, TOOLS, & CHECKLISTS FROM THE FIELD

Volume II is a compilation of assessment instruments, tools, or checklists. These instruments were submitted by active professionals in the field of assistive technology and demonstrate the range of instrumentation in use today. Each item submitted is reviewed according to a format. It is anticipated that this will become an evolving document.

VOLUME III: RESNA RESOURCE GUIDE FOR ASSISTIVE TECHNOLOGY OUTCOMES: DEVELOPING DOMAINS OF NEED AND CRITERIA OF SERVICES

Volume III provides explanation of domains of anticipated assistive technology impact across functional areas of an individual's life.



### CONCEPTS AND RATIONALE FOR ACCOUNTABILITY IN ASSISTIVE TECHNOLOGY

### Frank DeRuyter, Ph.D.

"Each day, each product or service is getting relatively better or relatively worse, but it never stands still." Tom Peters

The relationship between the delivery of goods and/or services and the consequential outcomes has been long recognized. Throughout the past century, there have been many examples in which the manufacturing and service delivery sectors have strongly advocated the employment of various objective measurements to improve upon the delivery of goods and services. In recent years, the escalating importance that society has ordered on accountability, performance monitoring and personal responsibility has led to an increased emphasis being placed on the monitoring of service delivery practices and the evaluation of outcomes. This renewed emphasis however, has placed certain areas of the service delivery sector into a state of confusion because it is usually harder to evaluate the services than the goods. One cannot always "kick the tires" before a service is delivered. By the same token, it is equally difficult to "return a service" to a complaint department. Within the assistive technology arena, the various stakeholders have begun to realize the validity of this statement as well as the accompanying difficulties in the development of performance monitoring and accountability systems as it responds to this dilemma.

### **OVERVIEW**

The demand for assistive technology services continues to grow at a very rapid pace. This is in light of the fact that the costs for assistive technology have become significant and are frequently a lifelong expense. During the past three years, the clinical service delivery sector throughout the United States has witnessed several significant events that raise serious questions about the availability of resources in the future. These events have included: (1) a political realignment to a new national public policy agenda shifting from a social-ethical agenda where consumers have had access to goods and services irrespective of cost to an economic agenda where the access to goods and services is being driven by cost and a pricing paradigm; (2) an ongoing national expenditure crisis; and, (3) dramatic changes to the global economy. The potential consequence of each of these events is that for the first time the assistive technology community



Volume I: RESNA Resource Guide for Assistive Technology Outcomes: Measurement Tools

stands to find itself at great risk about whether it will be able to deliver its current level of goods and services in the future. Especially in light of the fact that the dollars available in the future are most likely to decline. One can only hope for the best case scenario which will be that the current dollars available to meet the demand will remain unchanged.

For the reasons stated above, it becomes imperative that the various stakeholders within the assistive technology community identify alternative and more efficient ways of delivering goods and services as well as begin developing performance monitoring systems in order to be held to a higher degree of accountability than has been executed to date. The providers of assistive technology goods and services must demonstrate positive outcomes of high value and at a reasonable price. This will necessitate that all assistive technology stakeholders come to terms with whether the expenses associated with assistive technology goods and services justify the benefits gained. Accountability today will minimize the denial of goods and services tomorrow.

Accountability and performance monitoring within the assistive technology clinical service delivery sector will provide the qualitative and quantitative data that evaluates the comprehensiveness, effectiveness and the efficacy of the services provided. This information should specifically ascertain the **value** as well as **best practices** of practitioners, services, products and programs alike. At a minimum, the evaluation process must measure and establish a baseline of what works; identify how well and for whom it works; and, determine at what level of economic efficiency it works. The process whereby data are selected to answer these questions will require taking information from several performance monitoring dimensions. This process has also been referred to as outcomes management. In the clinical service delivery sector, frequently used dimensions have included clinical status/results; functional status; quality of life; satisfaction; and, cost.

Accountability, performance monitoring and outcomes management is frequently conducted within the framework of continuous quality improvement (CQI). Data are correlated with specific processes or systems that may be modified, thereby enhancing the effectiveness and efficiency of service delivery, ultimately improving the outcome. This process has also more recently been referred to as total quality management (TQM). Measuring performance and outcomes provides the greatest indication that process or system changes are in fact improving quality levels. Over the past several years, numerous clinical service delivery environments have begun to clearly demonstrate that these initiatives have actually improved patient/client outcomes and have decreased the variations in clinical practice. Despite the conventional wisdom that better quality



costs more, it has been determined that in the long run, good care usually costs less than poor care. In fact, several leading practitioners claim that the best way to reduce costs is to improve quality (DeRuyter, 1997).

### RATIONALE FOR ACCOUNTABILITY

### Quality mandate in assistive technology

The quality mandate and its focus are not a recent phenomenon. It has been said on numerous occasions that quality is an entity that exists in the eye of the beholder and that therefore quality is simply a perception. With that said, however, it is also important to acknowledge that perceptions form expectations that become the realities. The assistive technology community must therefore measure as well as manage those perceptions in order to be accountable. Furthermore, this accountability must be accepted in all aspects of assistive technology and by all stakeholders.

Over the past century, many have advocated different objective measures to improve upon the delivery of various products and services within the manufacturing sector. In the clinical service delivery arena, Florence Nightingale is probably most widely credited with incorporating the first scientific approach at evaluating quality. It has only been over the past three decades, however, that an increased importance has been placed on accountability and performance monitoring as it relates to clinical activities within the healthcare and educational sectors. This monitoring has focused primarily on trying to measure the quality of care provided, although recently the emphasis has shifted toward measuring clinical and cost outcomes. Ironically, the assistive technology community has generally exhibited reluctance at being held accountable until just recently. This has been in spite of several assistive technology stakeholders that come from sectors that have embraced performance monitoring for a number of years.

Much of the present day quality mandate within the clinical service delivery sector has been driven by activities that began in the late 1960's. These early efforts were in fact retrospective utilization plans adopted by both healthcare and education. These early quality measurement activities led to the development of professional standards review organizations in the 1970's which attempted to evaluate the quality of service provided. These efforts rapidly led to the development of peer review organizations and eventually quality assurance programming. Both of these efforts were designed to monitor the quality of services provided, however, these efforts only focused on chart audits and client satisfaction surveys designed to ascertain what people were complaining about and/or what had gone wrong. Great concern was articulated by clinical service providers



during this period because they believed they were being asked to participate in a process that in reality could never be assured. Despite the quality decrees of the 70's and 80's, clinical service providers had few compelling reasons to be accountable or to measure and demonstrate quality. Consequently, performance monitoring was frequently ignored, as there were few incentives to account for "doing the right thing" let alone examine the effectiveness of the clinical services that one delivered. As a result, quality was acclaimed as an idealistic goal that was too difficult to measure, let alone define, and accountability remained as an esoteric concept.

By the mid 1980's, the attitude toward accountability and quality began to change. Many service delivery sectors witnessed economic difficulties associated with the national deficit spending crisis. This resulted in an era of diminished resources within the education and healthcare sectors. As policy changes and budget cuts impacted upon these sectors, it was frequently argued that quality would be severely impacted. However, the laissez-faire attitudes that were asserted toward quality during the 1970's and 1980's meant that there was only minimal data, often anecdotal, to support this contention. Consequently, the incentives to survive overshadowed doing the right thing. The end result to the clinical service delivery sector was devastating for both consumers and providers. This was evidenced through widespread organizational reengineering; denied or limited access to services; poorer quality; and even the outright elimination of services.

By the late 1980's, consumers were quick to realize the impact of what was occurring which resulted in a major public outcry. This marks another period of major change. For clinical service providers the impact was referred to as a paradigm shift and focused specifically on numerous new requirements. These led to the monitoring of program activities as well as for the first time the monitoring and accountability of providers. These changes ultimately became known as quality assessment and improvement. More recently, this has been referred to as performance monitoring. Today, care provided by the clinical service delivery sector is being managed and evaluated on an ongoing basis in order to minimize the associated costs and to maximize the desired outcomes. Furthermore, clinical service provider agencies and facilities must now include providers and consumers as active participants throughout the entire ongoing evaluation process.

### Scope of assistive technology practice and need for quality

It has been previously stated that the assistive technology community was able to remain on the fringe of the performance monitoring and accountability agenda for several years. It has been debated whether this has been an asset or a liability to the assistive technology community. Irrespective of the merits of the arguments, it is important to acknowledge that there are some very



specific aspects of the scope of assistive technology service delivery practice that have had a profound influence over the ability to effectively participate in the performance monitoring and accountability agenda let alone agree on the need for quality. By not having adequately developed performance monitoring systems, serious questions regarding the effectiveness and efficiency of the assistive technology service delivery system as well as the efficacy of the provision of these services have been raised. There are those within the assistive technology community who have simply operated under the assumption that accountability and improved outcomes are derived through better technological solutions. As a result, technological solutions have been looked toward for improved outcomes without data to support the assumption. With the knowledge that almost one third of all devices are likely to be abandoned (Phillips, 1992), this view has been rather myopic. With the excitement toward high tech solutions moderating, a renewed emphasis on performance monitoring that examines the validity and benefits of the technological solutions appears to be taking place.

Over the past few years, numerous conference presentations and several publications have begun to address performance monitoring as it relates to assistive technology. Although there is still a paucity of information, the assistive technology community has not entirely been without performance monitoring activities. At a system level, several articles have addressed the need to establish some type of the accountability (Blackstone, 1990; DeRuyter, 1992a, 1992b, 1995; Jutai et al, 1996; NIDRR, 1994; Smith, 1992; Warren, 1992, 1993). These efforts have been focused at several areas including those that were service specific (AAC, access, mobility, etc.); institutional specific (pediatric rehabilitation); organizational specific (RESNA); and, agency specific (NIDRR). All of these efforts, however, began after there was a legislated mandate to provide services and equipment. Consequently, the assistive technology service delivery community has been "in the position of having to deal with the cart being before the horse" (Warren, 1993).

There have also been a number of single case studies or small sample size reports. Some of the major studies include the following: a follow-up survey of prototype vocational aids for the blind (Brabyn, 1981); a follow-up survey of the various devices still being used 16 weeks after device delivery (Caudrey & Seeger, 1983); a retrospective study of client satisfaction with device function and comfort five years after delivery (Kohn et al, 1983); a telephone survey of device usage two weeks after delivery (McGrath et al, 1985); device utilization and quality of life (Scherer, 1988); a follow-up on the utilization of devices in rural areas (Willkomm, 1988); what separates high tech users from non-users (Scherer & McKee, 1990); a national survey on technology



abandonment (Phillips & Zhao, 1993); and post discharge device usage in relation to functional status (Cushman & Scherer, 1996). The greatest shortcoming of most of these reports is that they have consisted of retrospective reviews rather than prospective studies. As a result, these studies, which have been informative, have provided little insight into how to change the manner by which services are delivered or how to improve upon the quality of services provided.

In terms of long-term prospective assistive technology related performance monitoring only a handful of studies have been reported. These have included the following: the application and use of augmentative and alternative communication systems for 50 individuals who were nonspeaking as the result of traumatic brain injury and stroke (DeRuyter & Kennedy, 1990; DeRuyter, Kennedy & Doyle, 1990). Both of these studies impacted the delivery of services to these populations as they altered the traditional manner of providing AAC systems to all who were nonspeaking in these populations by identifying key variables as to when systems should be considered. In another prospective study, user feedback as it related to assistive technology was documented through standardized data collection at 5 different service delivery centers. These data were used to demonstrate that user satisfaction and device performance data could be collected and compared across service delivery sites with reliability (Kohn, LeBlanc & Mortola, 1994). In a more recent study, post discharge device use of 47 individuals in relation to their functional status was addressed (Cushman & Scherer, 1996). This report went on to document the discrepancies in perception between therapists and consumers regarding utility and aesthetic aspects of devices as well-as provide strategies to maximize appropriate device use. Finally, a recently completed longitudinal outcome study, followed over 100 children and adolescents each for over a two year period to examine the issues of usage and appropriateness of assistive technology as well as the underlying and contributing elements that ultimately influenced the outcomes (DeRuyter, in press). Each of these studies, which focused on some aspect of performance monitoring, are important to the assistive technology community because they have influenced and changed the way in that services are provided. It is these long-term, prospective type assistive technology-related performance monitoring studies that will effect positive changes in the delivery of assistive technology clinical services.

The assistive technology community has actually witnessed several other subtle efforts that have addressed the quality mandate. Probably most familiar is the "State Tech Act" legislation. In the 1994 amended reauthorization (PL 103-218) of the enabling legislation, Sections 102(e)(6-8) specify that recipients of the discretionary "Tech Act" grants must conduct annual assessments of 12



their program initiatives. In another effort, the American Medical Association in 1994 developed its *Guidelines for the Use of Assistive Technology: Evaluation Referral Prescription*. This was a major milestone for validating the provision of assistive technology services in the healthcare arena. These guidelines led to the inclusion of assistive technology services in the standards of the Commission on Accreditation of Rehabilitation Facilities (CARF), a major healthcare accreditation organization. As a result, the monitoring requirements for quality of care and program evaluation systems have necessitated many assistive technology providers in CARF accredited organizations to address these mandates. Numerous other initiatives at both the statewide and local levels of the educational service delivery sector as well as within the professional organizational level, such as RESNA, have begun to address the accountability and performance monitoring requirements for the clinical service delivery sectors. Finally, an increasing number of state and national legislative bills requiring accountability are being legislated. The result is that all stakeholders within the assistive technology community are being held to a new level of accountability and performance monitoring. Despite all of these efforts, there is still, however, no single measure that clearly satisfies all objectives and dimensions of the mandates (Smith, 1996).

### Assistive technology stakeholders of quality

Today, the performance monitoring and accountability placed on the clinical service delivery system has become the norm. Unlike quality assurance, the mandates appear to be more than a passing fancy. While practitioners were able to drive the clinical service delivery system for many years, today policymakers, payers, and consumers are driving the system. As discussed previously, consumer pressure has been a driving force behind the performance monitoring and accountability agenda. The disability community has certainly been a strong force in the quality movement. As consumers at large have become educated, they have demanded information, which has forced the clinical service delivery sector to not only define quality and outcomes but to describe them in performance terms. Whether it is doing things right the first time or doing the right thing, accountability, performance monitoring, and the evaluation of outcomes has become the expected norm. While this has been embraced widely for many years by manufacturing, it needs to be fully embraced by the assistive technology community. The difficult question for the assistive technology clinical service delivery sector to assess and answer will be in determining whether what it does is indeed the right thing to do and whether it was done efficiently. What is certain is that the second half of this decade will be hailed as one of accountability and it will be up to society to determine whether the scope of assistive technology practice was provided responsibly.



Inherent throughout the history of the development of the scope of assistive technology practice and its community has been an acknowledgment that the components and entities of this service delivery sector are exceedingly diverse. Confounding this has been the assumption that the service delivery sector requires the integration of these components and entities in order to be successful. While this premise is debatable, the bottom line is that there has been no objective assessment of the assumption, albeit numerous anecdotal reports appear to support the validity of the premise. As a result, the practice of assistive technology has evolved into a very complicated service delivery model.

Assistive technology consists of a multidisciplinary service delivery model that incorporates a multitude of stakeholders. The stakeholders embody a wide range of providers and agencies that come from many different sectors. As such, assistive technology services may be provided in a variety of service delivery settings. These include healthcare, educational, academic, or vocational settings; a manufacturer or vendor showroom; an independent living center; a research lab; a personal home; a private practice setting, just to name a few.

The array of stakeholders involved are as diverse as the service delivery settings. Stakeholders include: the consumer (primary and secondary), occupational and physical therapists, speech pathologists, rehabilitation engineers, manufacturers, vendors, payers, researchers, policy makers, and numerous others. It is easy to see how complicated the assistive technology service delivery model has become. All of this is compounded further when one realizes that in order to be accountable, the clinical service delivery system must respond to several different performance monitoring dimensions (clinical status/results; functional status; quality of life; satisfaction; and, cost) (DeRuyter, 1997). Each of these different dimensions in turn have varied significance to each of the different stakeholders, agencies, and sectors. While all stakeholders seek a successful outcome, not all stakeholders seek the same outcome. Therefore, what may be a successful outcome to one stakeholder group, may very likely be a "who cares" outcome to another stakeholder group. Figure I, "Perspectives of Different Stakeholders: Importance of Various Outcome Dimensions" lays out graphically the outcomes of interest to each stakeholder group. Figure II, "Perspectives of Different Stakeholders: Aspects of Assistive Technology Service Delivery" graphically portrays the aspects of service delivery, financial concerns, outcomes of interest, and research to stakeholders.

As the stakeholders throughout the assistive technology community continue to participate in accountability and performance monitoring activities there will be a further delineation of the



roles of the various stakeholders. In the eyes of many, it is only the client/patient who is in need of clinical services that is considered as the customer/consumer of assistive technology goods and services. This is a rather myopic view, which merits reconsideration. There is a high likelihood that in the further delineation of roles, a majority of assistive technology stakeholders will find themselves not only functioning as providers of goods and services but also find themselves as customers/consumers of assistive technology goods and services. This will have a profound positive effect on the quality of service within the assistive technology community because the significance of accountability and performance monitoring activities depends largely on the role of the stakeholder. Customers/consumers measure performance largely on an intuitive basis and have little interest in the issues that concern or relate to the providers of goods or services. Providers, on the other hand, are more concerned about the quantitative and qualitative aspects of the goods and services. A direct consequence of the clearer role delineation should be a better ability to understand both sides of the clinical service delivery process that can only enhance the quality of the goods and services provided. In the final analysis, all stakeholders in general and the assistive technology community at large will benefit from accountability and performance monitoring.



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# PERSPECTIVES OF DIFFERENT STAKEHOLDERS

## Importance of Various Outcome Dimensions

	CLINICAL RESULT	FUNCTIONAL	QUALITY OF LIFE	CONSUMER SATISFACTION	COST
ADMINISTRATOR	0N	Yes	N <sub>O</sub>	Yes	Yes
CLENT	9 V	Yes	Yes	Yes	Š
CLINICIAN	Yes	Yes	Yes	Yes	Ž
PAVER	Yes	Yes	Ž	Yes	Yes

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# PERSPECTIVES OF DIFFERENT STAKEHOLDERS

## Aspects of Assistive Technology Service Delivery

	SVC DELIVERY	FINANCIAL	OUTCOMES	RESEARCH
ADMINISTRATOR	Competition & Resources	Cost	Satisfaction & Cost	Zorm
CLIENT	Consumer Satisfaction	Cost Utility	Satisfaction & QOL	No Harm
CLINICIAN	Clinical	Cost Benefit	Functional	Outlier (unusual case)
PAYER	Resource Allocation	Cost	Cost & Satisfaction	Norm & Outlier

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### ACCOUNTABILITY IN ASSISTIVE TECHNOLOGY INTERVENTIONS: MEASURING OUTCOMES

### Roger O. Smith, Ph.D., OT, FAOTA

### Hierarchy in the Complexity of Assistive Technology Outcomes

It is as simple as needing to know whether assistive technology works. A consumer assumes that a device, when purchased, should work. This is particularly true when experts are helping to select the best devices. The simplicity, however, quickly eludes us. Very little information is available which empirically demonstrates the usefulness of an assistive technology device. Furthermore, in most situations we need to choose an assistive technology device from an array of assistive technology options. Therefore the question is not "Does assistive technology work?" but rather "Which assistive technology devices work best?"

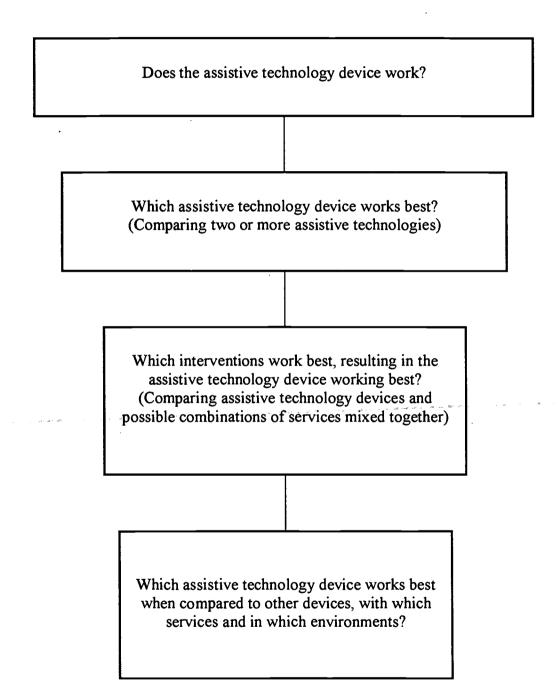
We also know that assistive technology is not an appliance, which when plugged in works by itself. Most assistive technologies require some services for selecting, obtaining, fitting, adapting, designing, reevaluating, repairing, and updating the technology. In fact, the federal "Tech Act" definition of assistive technology clearly includes assistive technology devices and assistive technology services. This is an important acknowledgment. For examples, augmentative and alternative communication devices may require vocabulary programming, a computer access interface may need settings to be configured properly or a seating system may need to be assembled with selected accessories and be individually fitted to the user. Each of these services can make the difference between a useful and a useless assistive technology device.

Yet another dimension which can influence an assistive technology outcome is the environmental context. The environment for which the assistive technology is used interacts with the device and may match or mismatch. How well they match directly impacts the effectiveness of the assistive technology. How well an assistive technology system fits individual preferences, family values, cultural beliefs, and resources available in the environment delineates the outcome.

Measuring the effectiveness of an assistive technology device is simple. In its context, however, outcome measurement multiplies in difficulty. Figure 1 highlights the increasing complexity of outcome questions.



### Increasing Complexity of Assistive Technology Accountability





### What Assistive Technology Intervention Are We Measuring?

In 1985, Barry Rodgers highlighted 19 steps in the assistive technology service delivery process in a paper entitled, "A future perspective on the holistic use of technology for people with disabilities." These 19 steps detailed the spectrum of steps required of a service provider to implement an assistive technology system. See Figure 2 for the complete listing. These steps included tasks such as identifying the need an individual has for assistive technology, securing the funding, evaluating the individual who may be using the assistive technology for their abilities and disabilities, assessing the features and alternatives available which this individual might use, matching the individual to the technology, ordering the technology, delivering and fitting the technology once it arrived, re-evaluating the individual's performance with the assistive technology, designing a follow-up evaluation process, and providing on-going maintenance to keep the assistive technology working.

A key concept from the Rodgers' work is as important today as it was in 1985: of the 19 Rodgers' tasks only one focuses on assistive technology device selection. The other 18 are service tasks essential to support the effective use of the device. Acknowledging the existence of these 19 components of the service delivery process is extremely relevant to outcome measurement. Failure in any one step in this service delivery process can result in failure of the assistive technology intervention. Thus, an outcome measure needs to be linked to a complete description of services. Otherwise, the services contributed to the outcome will not be clear. (From research design terminology, an outcome investigation needs to have an independent variable and a dependent variable).

### Major Domains of Outcome

### Two Simple Domains of Outcome

While on one hand describing the assistive technology intervention (the independent variable) is more complex than it superficially appears, the quest for understanding the outcome variable can be described simply. Figure 3 highlights that there are essentially two domains of outcome. These primary dimensions are 1) the performance of an individual using assistive technology and 2) the cost of achieving that level of performance. Minkel (1996) highlighted that the value of the assistive technology is the basic formula of outcome divided by cost. Many other outcome measures do exit. Others, however, can be described as proxies, subsets, precursors or some type of contributor to these two primary dimensions.



### Figure 2

### COMPONENTS OF A "HOLISTIC" DELIVERY SYSTEM

An excerpt from "The Holistic Application of High Technology for Conversation, Writing, and Computer Access Aid Systems." In Chapter One, Roger Smith refers to this paper written by Barry Rodgers which details the components of a service delivery system:

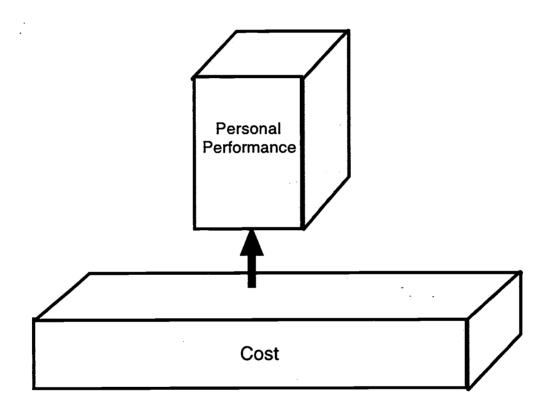
"The holistic application of a high tech aid system will require the following components:

- 1) Locating people who can make use of the aid system.
- 2) Establishing their needs and capabilities and the potential benefits of an aid system.
- Selecting and acquiring appropriate system components including special market hardware and software, and general market hardware and software
- 4) Making simple modification to hardware and software if necessary to make it compatible.
- 5) Assembling the aid system.
- 6) Mounting the aid system on the user's wheelchair, shoulder bag, bed, etc.
- 7) Fitting the aid system to the user including adjustments, modifications, and initial customization.
- 8) Selecting the most effective aid system training aids (manuals, video tapes, demonstration programs, etc.)
- 9) Initially training the user in the basics of the system and how to optimize it for themselves.
- 10) Training the people in the users environment who will need to help the user maintain the aid system.
- 11) Providing ongoing training to make sure users get all possible benefit from the aid system.
- 12) Being on call to answer subsequent questions about the aid system as it is being used.
- 13) Providing ongoing preventive maintenance and replacement worn-out parts.
- 14) Providing repairs.
- 15) Updating the system when significant improvements in available functions make it desirable.
- 16) Periodically evaluating the degree of integration of the aid system in the user's life and providing suggestions or further training as necessary.
- 17) Using information gained from users in the refinement and improvement of the aid system.
- 18) Providing a different more appropriate aid system when the user's needs or capabilities change.
- 19) Providing a different, more appropriate aid system when significant advances in aid system design make more useful aid systems available.



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### Figure 3 Two Essential Domains of Outcome



Value = Outcome / Cost (Minkel, 1996)



This two dimensional model suggests that there are four potential combinations. The worst outcome would be an individual who has a very low performance at a high cost. The most positive outcome, then, would be a very high performance of an individual using assistive technology at a very low cost. The two mediocre combinations would be high performance at high cost or low performance at low cost (see Figure 4). Cost-benefit types of outcome studies must ultimately speak to how well an assistive technology fits into one or more of these quadrants.

### **Types of Performance**

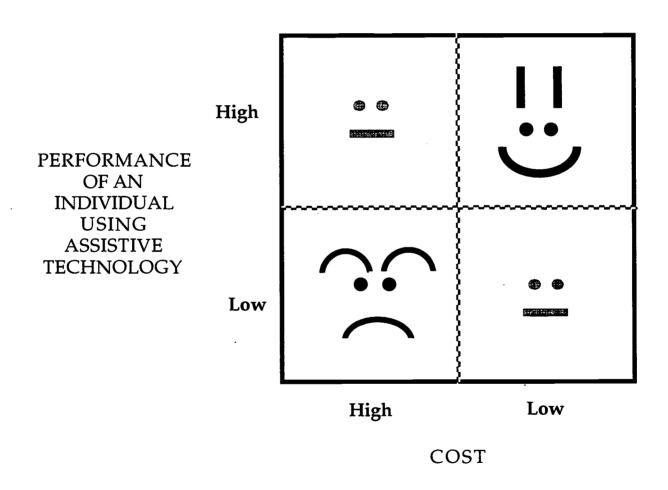
Personal performance, however, interacts with other dimensions that impact performance from the environment. Figure 5 shows the fundamental building blocks of Personal Performance with the addition of Intervention Performance and Support Performance blocks. Personal Performance includes domains of self-care functioning, such as toileting, dressing, mobility, bathing and other traditional rehabilitation activities of daily living. Personal Performance also includes what in the gerontological literature are called instrumental activities of daily living, such as community mobility, participation in community activities, and home management tasks. Many of the more traditional functional performance instruments from the rehabilitation professions fall within this category of personal performance assessment.

Intervention Performance is of primary interest to program administrators. Program evaluation and quality assurance activities often examine the adequacy and effectiveness of a particular intervention or program. Assistive technology assessments, which collect data to examine the service delivery process or focus on the features of an assistive technology device, are types of intervention performance assessments. Data that are collected to examine durability of equipment, provide specifications of an assistive technology device or system, or test the usability of a technology examine intervention performance outcomes.

Support Performance includes the systems around the user of assistive technology. Support systems facilitate the successful acquisition, integration and continuing implementation of the assistive technology. Availability of funding, financial services and assistive technology experts evaluation team, supportive family or community, vendors, maintenance facilities, medical services, vocational or educational services, information brokers and access to case managers contribute to the performance of the support structures within the service delivery system.

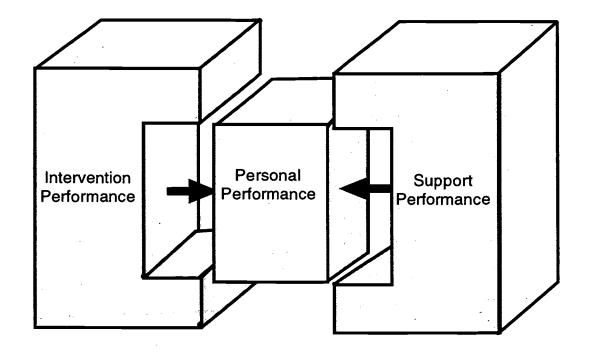


### Figure 4 Simplicity of Assistive Technology Outcomes





### Figure 5 Three Types of Performance





Personal Performance, Intervention Performance and Support Performance, along with the cost of achieving these levels of performance must operate together as a single unit.

### The Importance of Subjective Dimensions of Outcome

In an ideal world we would be easily able to measure performance. In the real world, however, it is not easy to measure how an individual performs in the activities important to them. Likewise it is difficult to measure the performance of interventions, or support systems. Consequently, measurement instrumentation has received substantial attention over the last decade to facilitate the ease and improve the quality of collecting data. This has led to the development of numerous subjective measures of outcome. Subjective data instruments provide us with a method of collecting outcome information parallel to objective data instruments. The four outcome dimensions (Personal Performance, Intervention Performance, Support Performance and Cost) can be measured using objective or subjective data collection techniques. Subjective performance measures often manifest in the forms of user satisfaction surveys, selfsatisfaction questionnaires, quality of life instruments, or preference inventories. While these methods of data collection are often not viewed as examining performance, at closer examination, these types of instruments do address performance outcomes. For example, the user satisfaction questionnaire, which asks an individual how, satisfied they are about a wheelchair and its features are a subjective measure of the assistive technology Intervention Performance. Or quality of life inventories such as the Sickness Impact Profile or the SF-36 elicit the perspective of the individual on their health and other aspects of Personal Performance. In the supplier industry, customer satisfaction questionnaires often address aspects of Intervention and Support Performance.

These types of subjective data instruments make important contributions to the outcome field. They provide:

- a) Important perspectives which undergird performance. For example, how an individual feels about the assistive technology they use has a primary impact on their functional Personal Performance while using the technology.
- b) Subjective questionnaires often serve as an excellent proxy for functional performance and other outcomes. How an individual views their personal health to services provided or the assistive technology devices can be a window into the actual performance.



- c) Subjective data can be extremely practical to collect. Directly eliciting responses from an individual through a simple questionnaire can replace the need for direct observation or standardized assessment procedures. This is efficient. Delivering a questionnaire to an individual does not require professional time. Also, the quality of the data can be good, as individuals who are using services or devices have a personal investment in returning good feedback.
- d) Philosophically, it is highly appropriate to involve the end user in the data collection process. Subjective measurement instruments require this involvement.

Cost seems to be one of the outcome domains, which specifically seems to be conducive to collecting objective data as opposed to eliciting user perspective information. However, there are powerful benefits in securing end-user subjective cost data. One might ask any marketing agency or the marketing department from any business how they determine the feasibility and prospect of sales of any product. They will immediately highlight that the cost of the product becomes a primary consideration. This cost however, is not the actual price, but the potential customer's perceived price of a product in the context of the customer's perceived product value. Secondly, obtaining the real cost of any product or service is deceptively simple. The cost of a product or service is not the price or charge for a device or service. The actual cost includes the direct and indirect expenses that accrue in the development, manufacture and delivery of any product or service. Keen accounting and high caliber detective work is often required to even approximate the real cost of any product or service. This, in fact, is one of the primary challenges in the economic evaluation of any health-related technology

Figure 6 portrays the three dimensional block which includes the cost block on the bottom, Personal, Intervention, and Support Performance blocks on the top. Blocks representing objective outcome measures are in the front and parallel blocks in the back represent the subjective outcome measures.

### All Roads Should Lead to the Top of the Mountain

We need to develop many successful routes to the top of the outcome mountain. We will encounter barricades, weather erosion, and inclines that are too steep to climb, and fatigue of our packhorses. However, we must remain cognizant of the reason we are blazing all these new routes to the top of the mountain. Fundamentally, we want to know how well an assistive technology device and service works to improve Personal Performance at what cost. (See Figure 7.) This mountain metaphor, as simplistic as it seems, points out an important issue surrounding



### Figure 6 Subjective and Objective Dimensions of Outcome Data

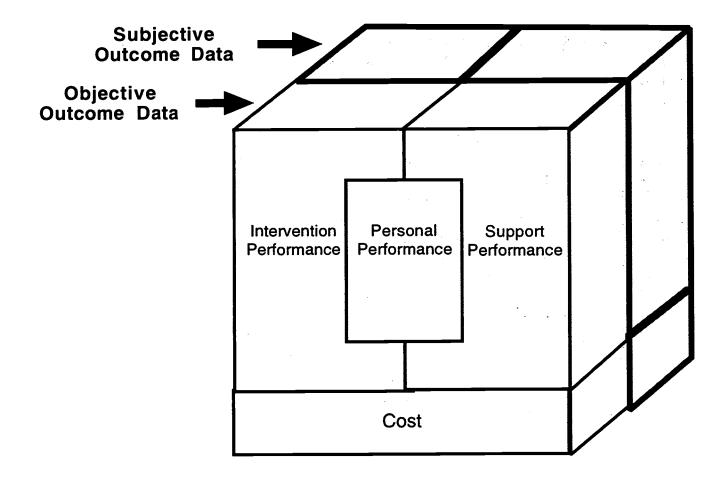
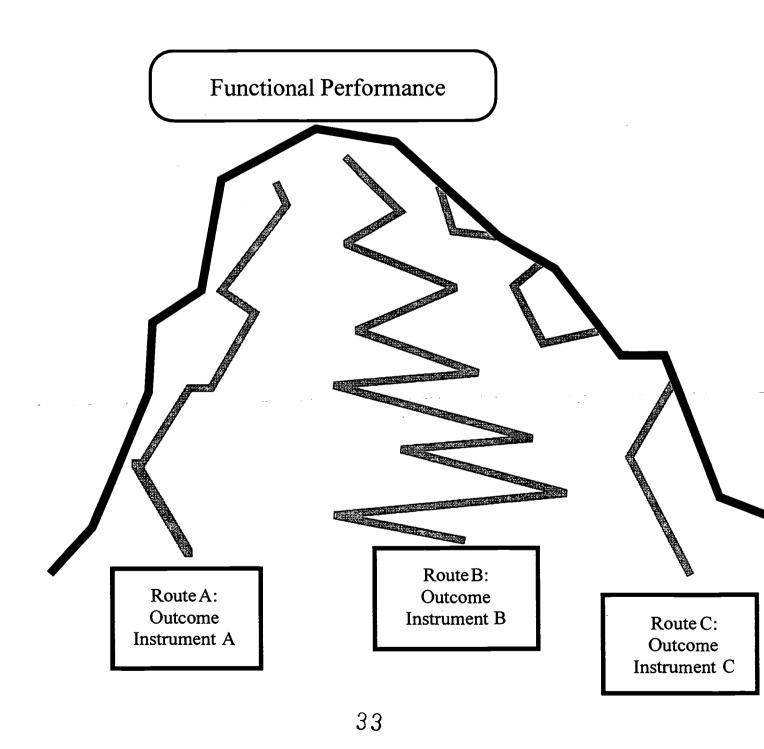




Figure 7
Many Outcome Instruments Provide Routes to Estimate
Real Functional Performance





outcome measurement. Until the perfect outcome measure is found, we need to be creating new ways to achieve our goals of measuring outcome.

### **Taxonomy of Outcomes**

### What to Measure

In 1996, during an American Occupational Therapy Association Conference, Jennifer Angelo and Joy Hammel held a Nominal Focus Group to collect data on the question of what is assistive technology outcome in occupational therapy (Angelo & Hammel, 1996). This gathering of occupational therapists with assistive technology expertise (76% were members of AOTA Technology Special Interest Section) highlighted the breadth and depth of what professionals often consider to be areas of outcome. Figure 8 lists the items generated in three groups from this group session. It can be seen that these range from global success in returning to life activities, to the subjective satisfaction of life activities, to the serviceability of devices, to being able to better use a computer. This array of types of outcomes is the perspective of only one profession at one point in time. The list would be even more extensive across a wider group. If one of our goals is to better measure outcomes, we must organize the countless types of outcomes. Various approaches have been used to classify outcome areas.

### The Disability Models

Many authors, agencies and organizations have tried to provide a taxonomic framework around outcomes relevant to interventions offered for people with disabilities. This section reviews many of the prominent taxonomic approaches. These taxonomies have been generated and promoted from medical and health organizations, medical rehabilitation agencies and organizations, rehabilitation related therapy and engineering perspectives. While there are many similarities to these ways of looking at outcome, each has a unique flavor and contribution to how we view the importance of outcome and which areas are emphasized. In 1993 the National Center for Medical Rehabilitation Research (NCMRR) of the National Institutes of Health compiled an effective overview of disability classification schemes from that time (National Center for Medical Rehabilitation Research, 1993). They discussed the model from the World Health Organization (disease, impairment, disability, and handicap) from the early 1980's, the model from Nagi (1991) which formulated the Disability in America model in 1991 (pathophysiology, impairment, functional limitations, and disability), the Public Health Service



### **GROUP 1**

- 1. To pay income tax
- 2. Ability to perform with able bodied
- 3. Cost effectiveness
- 4. Assistive technology within the context of other intervention strategies, a one-stop shopping concept
- 5. Life role performance
- 6. Assistive technology as a tool for consumers to meet multiple needs (such as when they are teaching and working)
- 7. Increase educational potential for work
- 8. Decrease reliance on social support systems
- 9. Increase independence in daily tasks (activities of daily living, work, play)
- 10. Occupational therapy's unique role in relation to function
- 11. Decrease functional impairments
- 12. Community integration (this is at the handicap level according to WHO)
- 13. Increase independence
- 14. Occupational therapist holistic approach as optimal AT discipline
- 15. Increase quality of life
- 16. Identify funding barriers/solutions. Get funding for occupational therapists, AT and AT services
- 17. Increase respect for occupational therapists role in AT among other professionals
- 18. Achieve goal/dream beyond AT
- 19. Identify barriers to achieving role performance (environment, community, attitudes awareness, social)
- 20. Demonstrate true definition of function
- 21. Recognition of OT by consumers, society, and funders
- 22. Efficiency of service delivery
- 23. Integration of AT teaching in professional programs
- 24. Joint occupational therapy and AT certification
- 25. Quality of AT/occupational therapy/AT services
- 26. Consumer satisfaction with occupational therapy/AT services
- 27. Having fun
- 28. Assistive technology versus other alternatives
- 29. Occupational therapy as At case managers
- 30. Team approach

### **GROUP 2**

- 1. Satisfaction for the client, care giver, and payor
- 2. More capable of employment
- 3. Decrease cost of subsequent medical care
- 4. Purchase in mass market. Meaning that this will decrease the cost and therefore more people will be able to buy it and benefit from using it
- 5. Able to meet a personal goal



- 6. Improve earning power
- 7. Amount of time they use it. It would be easy to measure the amount of time that individuals use it. This would be one outcome measure to demonstrate that it is necessary because they are using it frequently.
- 8. Number of additional tasks that can be performed
- 9. Decrease number of hours for care taker/paraprofessional
- 10. Allow independent living
- 11. Elderly live at home more independently
- 12. Quality of life
- 13. Increase number of life roles
- 14. How much faster, more efficiently can person complete task
- 15. Compatible or interface with devices used at the same time
- 16. Be able to participate in and graduate from school
- 17. Comparison of devices/solutions
- 18. Quantities of social relationship
- 19. Qualities of social relationship
- 20. Easy to use/user-friendly
- 21. Benefit of technology justifies the cost of the equipment/services
- 22. Esthetically pleasing
- 23. Decrease device abandonment
- 24. Serviceability

### GROUP 3

- 1. Betters AT devices for increased mobility given stairs and uneven services and better access to those aides
- 2. Did client use the AT devices that were provided? Did the client accept the device and was training given?
- 3. How independent are they in the environment such as at work or at school
- 4. Evaluate employability and employability using AT
- 5. Quality of life "seamless society" and be accepted by peers. People should not be set apart in society because they cannot participate in certain activities due to a disability. Rather all people should have access to common activities side by side.
- 6. Good fit between person and AT device in the environment
- 7. Ability to pursue own interests, roles, and goals
- 8. Assessment is ongoing, of how individuals use AT and new ideas identified follow up
- 9. Express oneself (via computers) AT
- 10. Assess/implement in home environment (telemedicine) 2-way

\*Note: Items in Figure 8 are not listed in any particular order. They reflect initial brainstorming prior to clarification and evaluation stage of process.



Task Force (underlying cause, organ level, person level, and interaction of environment on person, family and community) and recommended the new NCMRR model which combined the benefits of these previous schemes. The NCMRR model continues to be promoted (Gray, Quatrano, & Lieberman, 1998) as it includes key features of the problems, which emerge from within the individual (pathophysiology, impairment, functional limitations, and disability), as well as highlights the interaction of societal limitation. This 1993 scheme defines pathophysiology as that process which interrupt or interfere with performance on the cell and tissue level. Impairment is defined as the loss or atypical performance of body organs or organ systems. Functional limitation is defined by this NCMRR scheme as a restriction or inability to perform actions or activities. Disability is defined as the inability or limitations to perform tasks within a physical and social context. Lastly, societal limitation is defined as restriction of performance, which are attributable to social policy or social barriers.

The previously mentioned disability taxonomies have several things in common. They tend to be presented in a linear fashion, move from a micro to a macro level, and focus on disability. Other taxonomies, however, break out of this linear thinking of disability. Some have built a larger model, which link disability toward ability, highlight interventions, and integrate the impact of the environment and environmental interventions on disability.

### The Balance Theory Model

One of these models emerges out of the industrial engineering (Smith & Sainfort, 1989) as a human factors engineering model it focuses on the relationship between the individual and the technology in the environment. This model suggests that the individual and function performance is in the center, with four components interacting and contributing to the individual's work abilities. The four contributing factors are the task itself (and its demands), the environment (defined as the physical work environment), the organization (forces such as management and scheduling), and the technology available for the individual to use. This model places the individual as only a component of an overall work system. As this model emerges from engineering, however, it is not encountered in medical taxonomy discussions.

### New Institute of Medicine Model

Recently, the Institute of Medicine (IOM) (Institutes of Medicine, 1997) updated their 1991 model and emphasized that the earlier models focusing on disability neglect to highlight the



importance of the relationship of the environment to the individual. (Brandt & Pope, 1997) Thus, the new IOM model consequently emphasizes the critical role the environment plays on pathology, impairment and functional limitation. The new IOM model generalizes the concept of societal limitation from being an endpoint on a continuum to posing the environment as having an effect on all areas of: a) no disabling condition to b) pathology, c) impairment, and d) functional limitation. Also, disability has been removed from the linear disability continuum. Disability has been redefined as one possible result of the interaction between the person and the environment. In fact, this latest IOM model of the enabling-disabling process omits the term disability from the taxonomy. The state of disability is not inherent in an individual, but is a result of the unique combination of the individual and the environment. This combination of performance leads to the ultimate quality of life.

### The HOPPIT Model

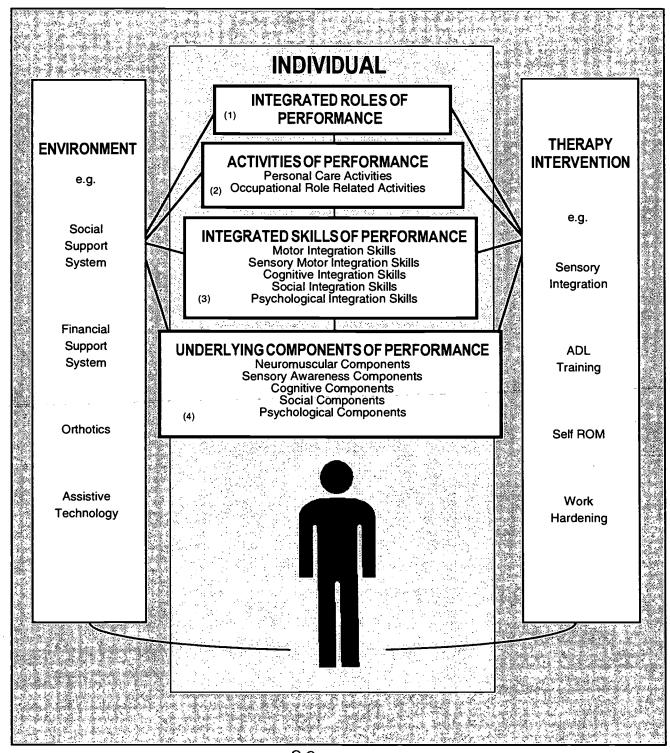
The Human Occupational Performance Practice Integration Theory (Smith, 1998) is a model which emerged from the American Occupational Therapy Association uniform terminology from 1979, 1989 and 1994. (American Occupational Therapy Program, 1989, 1994) The HOPPIT Model extends the AOTA uniform terminology and many of its concepts have been integrated into a functional assessment software package called OT (Smith, 1990, 1992 & 1994, 1995, 1998) OT FACT has been presented as one means for investigating the outcomes of assistive (Davel & Smith, 1996).

The relationship of outcome assessment areas according to the HOPPIT Model is attached as Figure 9. As can be seen, at the center of the model is the individual which includes four levels of functional performance. On the bottom level resides the underlying Components of Performance which include functional categories such as range of motion, pain, strength and memory. Above that lies the Integrated Skills of Performance that include categories such as hand function, problem solving and work tolerance. Above that are the Activities of Performance which include the traditional self-care activities, as well as traditional IADL vocational and educational role-related activities. On the top sits the Integrated Roles of Performance that include the various types of roles an individual might need to perform. Each of these levels of performance is dependent on all of the categories from the levels below.

To the side of the individual performer resides the Environment, which includes social support systems, financial support systems, orthotics, assistive technology and other



# Figure 9 Relationship of Outcome Assessment Areas





(Adapted from Smith 1991, 1995, 1998)

environmental factors. These environmental categories can affect any level of individual performance.

On the other side of the individual performance resides therapy intervention. This includes interventions such as sensory integration which focuses on the Underlying Components of Performance, to ADL training which focuses on the Activities of Performance, to self range of motion which focuses on the Activity of Performance, work hardening which would focus on the integrated skills of performance. Therapeutic intervention can interact with the Environment.

This is a comprehensive model of outcome, so the person's overall performance is dependent on the full combination of the environment, the individual and the therapeutic interventions.

Also advocated by the HOPPIT Model are the six approaches of intervention. Figure 10 highlights six approaches of intervention. These are categorized into three types: a) interventions which are due to performance changes of the individual (environment-free), b) approaches which are adjustments in the environment (environment-adjusted), and c) an approach which is dependent on another person (environment-assisted). The example in this figure is for an individual who is blind and is attending a lecture where slides are being shown. Approach #1 is to reduce the impairment, which would require the rehabilitation of vision so the individual can see the slides. Approach #2 would be to build compensatory skills, such as having the individual learn techniques such as asking questions to clarify the information during the lecture. Both Approach #1 and #2 are environment-free approaches. Approaches #3, 4 and 5 fall within the environmental-adjusted type. Approach #3 is to use assistive technologies such as obtaining an electronic copy of the overheads ahead of time and using a headset with a speech synthesizer. Approach #4 is to change the task. For example, the instructor could verbally describe the contents of the slides during the lecture. Approach #5 is to change the task expectations, such as making it okay to not read the slides. Perhaps reading the textbooks more carefully ahead of time would make the slides moot in terms of information. Lastly, Approach #6 is to use person assistance, such as having another student fill in any information gaps during or following the lecture.

The mechanism used by the HOPPIT model to differentiate between environment-free, environment-adjusted and environment-assisted data collection facilitates the ability to discriminate the impact of an assistive technology intervention from other interventions. For example, as in Figure 11, we could plot an individual's functional performance over time using



# Figure 10 6 Approaches of Intervention

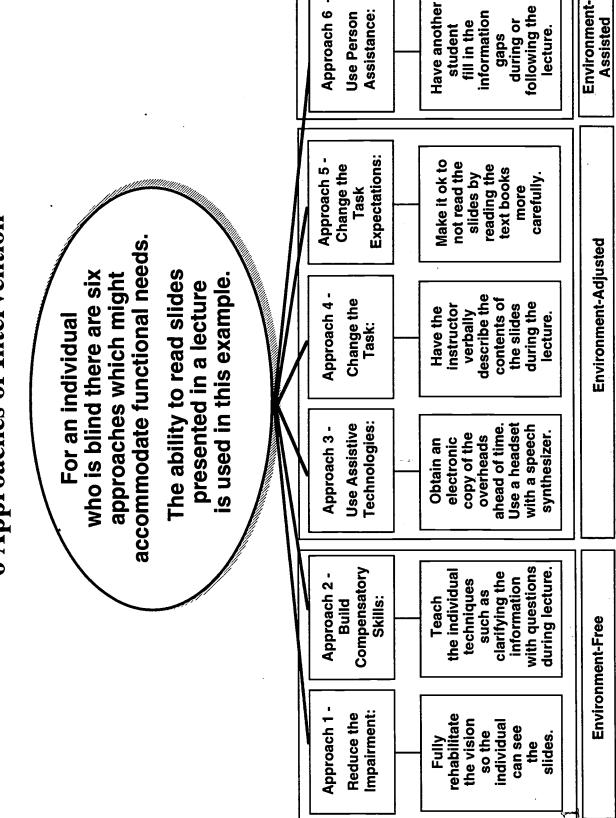
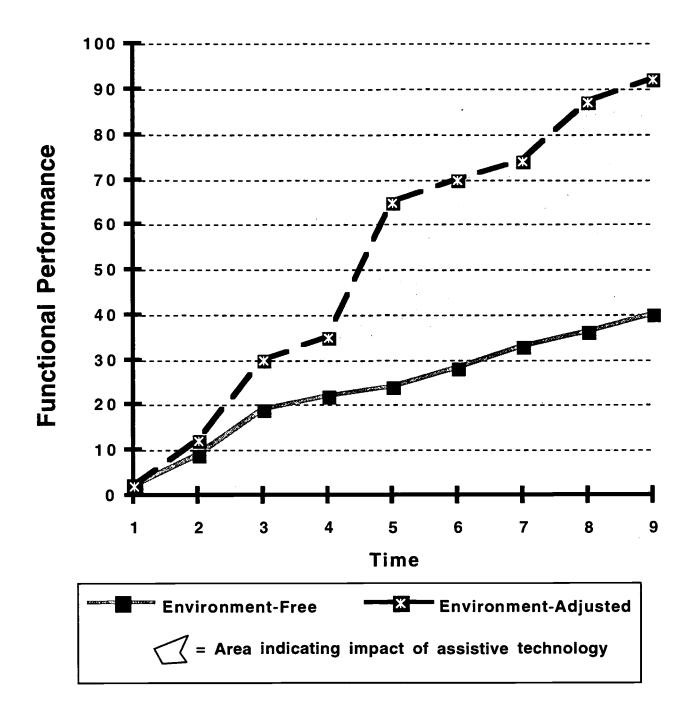




Figure 11
Environment-Free and Environment- Adjusted
Performance Over Time





an environment-free assessment. This would determine the performance of an individual with no environmental or outside assistance and monitor their progress. At the same time we could collect data using an environment-adjusted data collection format where assistive technology is provided to the individual and performance is ascertained with this environment-adjusted condition (Davel & Smith, 1996). Under this scenario, the area on the graph between the environment-free and environment-adjusted lines is the outcome specific to the assistive technology intervention.

#### **Outcome Measures for Assistive Technology**

#### **Traditional Instruments**

Volumes II and III of this RESNA resource guide identify the interest of the assistive technology field as it tries to define outcome measures, validate new methods for collecting reliable and valid data which can be used to examine assistive technology outcome. Ideally the field needs outcome measurement instruments to work across populations, settings, functional performance areas, assistive technology devices and assistive technology services. It would seem that the substantial attention and research in medical rehabilitation outcome assessment, some measures would have been developed which are appropriate. Typical rehabilitation functional assessment measures, however, even those that have become the foundations of rehabilitation outcomes research, are not designed from an assistive technology perspective. Stineman (Stineman, 1998) pointed out that the FIM (functional independence measure) and the SIP (sickness impact profile) are important as they collect data across a spectrum of populations. However, neither were created considering assistive technology, and in fact are missing essential components relevant to assistive technology. For example, in the FIM assistive technology is embedded into the seven-point scale so it cannot tease out the impact of assistive technology. Furthermore, the FIM does not allow the acquisition of a total score when an individual is using assistive technology, even though they may be as independent as an individual who is not using assistive technology (this is the case with all functional assessment measure which use a medical model designed from an environment-free perspective).

#### Relevance of the SF-36

The SF-36 instrument (Ware & Sherbourne, 1992) is relevant in the discussion of assistive technology outcome for three reasons. First, the SF-36 represents quality of life



instruments developed primarily to assess medical technology outcomes. These quality of life instruments are being used prolifically and having a tremendous impact on the financing and delivery of health-related technology. While many of these instruments are not designed to measure the impact of assistive technology, we have much to learn from these instruments in how they are applied, in how they uniquely collect quality of life data.

Secondly, the SF-36 is an instrument which is probably the most widely used in the world for measuring medical outcome. Hundreds of well-cited studies have used the SF-36 as a key data collection instrument. In fact, a volume of bibliographic entries documenting of SF-36 related studies is available. The development team of the SF-36 has also embarked on a major international project translating the SF-36 and validating the instrument for cultures and languages across the globe. As a part of the internationalization of the SF-36, very interesting discoveries are being made. One of these is a discovery of how sensitive the SF-36 is for discriminating quality of life differences among large populations. Ware (1997) pointed out at the International Congress on Performance Measurement and Improvement in Health Care that the translation of the SF-36 from American to British English uncovered an unexpected finding. One of the questions in the SF-36 asks the individual about how they would do in walking a mile. As the British system uses metric as opposed to the English mile, the SF-36 translation team converted the word mile to kilometer. While they understood that the kilometer was not exactly equal to a mile, both were long distances and it seemed would be functionally equivalent. What resulted was that the British group encountered the kilometer to be easier to walk than the mile. The SF-36 in its relatively few number of questions which target global health-related questions, discriminated subtlely between one long distance and another long distance.

Third, investigations using the SF-36 are finding perplexing results which may relate to interventions such as assistive technology. A team from Italy found substantial differences in quality of life between northern and southern Italy. They thought that these differences might be explained by the demographic differences. So, they examined age, medical case mix, gender, and a variety of socioeconomic factors. None of the large number of demographic variables scrutinized explained the differences between the perceived quality of life differences between northern and southern Italy (Apolone, 1997). The phenomenon of unexplained differences between populations is relatively common within the SF-36 data. Ware has clearly stated the widespread interest in identifying causes of these differences (1997).

The significance to assistive technology is that when asked, authors of the Italian study



and Ware agreed that rehabilitative interventions such as occupational and physical therapy and the use of assistive technology might be plausible explanations for these quality of life differences. Rehabilitation intervention variables, however, are not identified. In fact, data pertaining to these interventions is not collected in most health technology assessment investigations. The SF-36 research teams agreed that further investigation along this line is well warranted.

While the SF-36 is an extremely global measure of quality of life, when used in large numbers it discriminates well between interventions. It may be prudent for assistive technology outcomes research to consider the SF-36 as an additional data collection platform.

# **Economic Evaluation of Assistive Technology Interventions**The QALY

The logical extension of quality of life outcomes is to examine the cost compared to benefits of an intervention. Oldridge reviewed the health-related quality of life strategies and economic evaluation methods, suggesting the relevance to assistive technology outcome measurement (Oldridge, 1996a;1996b) Measurement methods such as the time trade-off technique, the basic lottery ticket and the thermometer are useful for comparing the qualities of possible outcomes of an intervention. Also, for comparing interventions these quality of life results can be integrated into an economic formula creating "quality adjusted life years", also known as QALY's.

There is some dissension regarding the appropriateness of using QALY's to measure outcomes of people with disabilities (Wolfensberger, 1994). There also remain issues pertaining to the reliability of QALY's and the subjective nature of its preferential-type data. For example, people with different perspectives will weight the outcomes differently (Richardson & Nord, 1997). Nevertheless, this type of data collection based on user opinion is gaining not only attention, but also increased usage in practice. The health technology assessment and health systems analysis literature documents numerous studies using decision analysis methods such as OALY's.

To date, few economic evaluations have been performed which examine the cost comparing benefits related to assistive technology (see cost effectiveness, cost efficacy and cost utility in the earlier chapter by DuRuyter). Applications and adaptations of these methods, however, deserve careful scrutiny as outcomes resemble methodologies addressing assistive



technology. One research track in Europe has taken an international team to examine the costbenefit of assistive technology. While these studies are preliminary, this is clearly new territory foraged by this team.

#### The CERTAIN Project

The CERTAIN Project (Cost Effective Rehabilitation Technology through Appropriate Indicators) was orchestrated by the Technology Initiative for Disabled and Elderly (TIDE) as a program of the European Union. This particular project, based in Italy, investigated the feasibility using mainstream health care technology assessment measures, a new cost-outcome method, and a Quality of Adjusted Life Years approach for application in assistive technology (Andrich, Ferrario, & Moi, 1998). The methodology was a retrospective study of seven cases representing a wide range of ages, diagnoses, levels of disability, and types of assistive technology used.

The research team considered five domains of outcome. These were 1) Context of outcome (e.g., culture, demographics, and experiences), 2) Individual goal expectation (including individual performance and social relationships), 3) Family expectations, 4) Professional's expectations, and 5) Outcomes with community activity. Costs were extensively examined. Careful scrutiny was taken to collect both assistive technology device and assistive technology service cost data across both direct and indirect expenditures.

Several measure of quality of life and functional performance outcome were used, including the FIM, EuroQol, Index of Health-Related Quality of Life and the MacMaster Health Classification System. Some adaptations of these instruments were necessary to better focus on assistive technology.

The CERTAIN Project revealed several findings of significance to assistive technology outcomes research. Regarding the FIM, it was found to report the performance outcome of assistive technology in an uneven way. When an assistive technology device was a direct support specific to a FIM area of function it was sensitive. However, when an assistive technology device addressed functions outside of FIM categories or implemented environmental adaptations, the FIM did not exhibit the impact of the assistive technology. Regarding the health quality of life assessments which the project used as utility scales, there were five major results (Ferrario, 1996). First, the generic quality of life measures used ineffective terminology. For example, questions reflected expectations that the individual was walking. These questions must be re-



phrased when used with people with disabilities. Second, the weighting of the scales used in the traditional scaling of the quality of life instruments reduced the changes detected to almost zero. Again customization of these general quality of life scales is needed to highlight smaller, yet significant, quality of life improvements. Third, calculation of QALY's showed that with progressive disorders the long-term benefit of the assistive technology was subsumed by changing needs. Traditional quality of life instruments assume some stability. Often in real applications, however, an individual's state changes and therefore do the benefits and updated needs for the assistive technology. A downward "decay" or upward "habilitation" factor needs to be built into a disability quality of life model. Fourth, the timing of the quality of life changes for assistive technology users is not consistent and thwarts standard fixed time data collection intervals commonly used in general health assessment methodology. Acceptance of an assistive technology device, timing and appropriateness of assistive technology services, and learning curves for integrating sophisticated assistive technology into daily life all affect quality of life outcome and must be built into a quality of life model which targets people with disabilities. Lastly, orthodox quality of life instruments do not include the family or other primary supports. This dimension needs to be incorporated into quality of life.

Overall, the CERTAIN Project cuts a new path into the cost/outcome measurement methodology in assistive technology. This project demonstrated the relevance, promise and pitfalls of traditional health-technology assessment methods and instruments. These types of investigations are needed to move assistive technology outcome measurement forward. A new generation of instruments and methods is one the horizon. Perhaps the CERTAIN Project can launch the interest, activity, and support for this important undertaking.



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#### PROGRAM EVALUATION METHODS

#### Jan Galvin

#### Introduction

The structure of the U.S. health care system is changing rapidly, primarily in response to concerns about increased costs of health-related services. Many of these changes appear to challenge our view of the delivery of quality services. Expanding the information available on quality requires the development of valid measurement tools and routine access to the right data. The Institute of Medicine (IOM) has defined quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." This definition suggests that a.) Quality performance occurs on a continuum, theoretically ranging from the unacceptable to excellent; b.) The focus is on services provided by the delivery system; c.) Quality may be evaluated from the perspective of stakeholders; d.) Research evidence must be used to identify the services that improve healthrelated outcomes; and, e.) In the absence of scientific evidence regarding effectiveness, professional consensus can be used to develop criteria. This definition of quality illustrates the complexity of the concept and its evaluation. However, it also suggests that despite this complexity and the current dynamics of the health-care delivery system, much can be done to: identify and balance competing perspectives, establish a framework with explicit criteria by which services can be judged, and, facilitate appropriate information systems for monitoring and reporting. (McGlynn, 1997; Landrum, et al, 1995) Program evaluation is one tool that, if developed with care and skill, can be used in conjunction with outcomes measurement and management, and a commitment to continuous quality improvement, to provide quality, competitive services that meet consumer needs to their satisfaction.

#### **Program Evaluation**

Programs need to show that they are delivering what they promise. Program evaluation refers to the variety of information-gathering activities designed to assist in program development, function and ongoing improvement and show program managers, the organization and stakeholders what they are delivering.

Program evaluation has been utilized in social services since the late 1960s. In the early



seventies, education and health care began implementing program evaluation systems followed by acute medical rehabilitation in the late 1970s. Methods for determining what is evaluated and how it is to be evaluated have been refined over the past 20 years as have the methods of collection, moving from abstracting from narrative records on paper to highly automated pooled, multi-institutional databases. (Wilkerson & Johnston, 1997) Program evaluation is now considered a solid analytical approach to facilitating internal review of an organization's programs' effectiveness and efficiency, and to build evidence for external communications about the programs. (Wilkerson, in press) As the Assistive Technology field moves into developing outcomes measurement systems, we should look carefully at what has been developed in the acute medical rehabilitation field and choose judiciously from their hard work.

The concepts of outcomes measurement, outcomes management, program evaluation, and quality improvement are closely related, and the interchange of terms is often confusing.

(Forer, 1996)

Outcomes Measurement. The degree to which the program produces sustained practical improvement in patient function. (Johnston, Wilkerson, Maney, 1993)

Outcomes Management. "A technology of patient experience designed to help patients, payers, and providers make rational medical care-related choices based on better insight into the effect of these choices on the patient's life". (Ellwood, 1988)

Program Evaluation System. A system defined by customer and stakeholder needs that includes process evaluation, program efficiency, program effectiveness, impact, and outcome evaluation. A program evaluation system provides information an organization can use to improve performance to an agreed-on level that meets desired outcomes.

Quality Improvement. A system through which better and more efficient processes in an organization continuously raise the levels of performance and the outcomes of all functions, eliminating errors, and reduce costs. (MacDonnell, 1996)

## What is Program Evaluation?

Traditional evaluation literature (Knutson, 1969; Weiss, 1972) cites two major types of evaluation. First, *formative evaluation* is used in an ongoing program and serves to identify needed corrections and improvements in the service and/or program. A second model of program evaluation *summative evaluation* is used to determine whether a completed program was successful. However, the most important function of a program evaluation system is that it becomes



a continuous process of assessing client and program needs and objectives, and uses that information to improve the individual's and the program' performance. For this to occur, the organization must buy into program evaluation and outcomes management and must be committed to change.

CARF<sup>1</sup> has defined program evaluation as a "systematic procedure for determining the effectiveness and efficiency with which results are achieved by persons served during service delivery and following program completion, as well as the individual's satisfaction with them." Program evaluation management reports tell the facility/provider whether its performance is acceptable according to the goals, objectives, and expectancy levels that the facility/provider has established for itself. (CARF, 1995)

JCAHO<sup>2</sup> specifies a process that involves four functions.

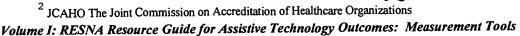
- 1. Identifying the most important aspects of care and service an organization, a department, or a program provides;
- 2. Using measurable indicators to systematically monitor these aspects of care and service in an ongoing way;
- 3. Evaluating the care and service, when predetermined thresholds are reached, to identify opportunities to improve the quality of car and service;
- 4. Taking actions to improve care and service or to solve problems, and evaluating the effectiveness of these actions. (JCAHO, 1992)

Program evaluation involves setting goals and expectancies. If goals are not attained, action should be taken to determine why. Program evaluation systems should be used to help make decisions about programs and as a tool for program improvement. (Johnston, Wilkerson, Maney, 1993). A program evaluation system can be very simple and inexpensive or very complex and computerized. Whichever framework is chosen for program evaluation the system must be able to measure the efficacy of services, the effectiveness of services and program, and the efficiency of services provided. (Wilkerson, in press) Regardless of the organizations' size and complexity there are a number of basic elements that must be present if the organization is to measure and manage outcomes successfully. These are:

#### mission statement

A mission statement should reflect the essential reason that an organization exists usually expressed

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<sup>&</sup>lt;sup>1</sup> CARF...The Rehabilitation Accreditation Commission

in one sentence. A mission statement helps people outside the organization gain a general understanding of the organization's mission and the needs that it is meeting. It also helps those developing a program to really narrow down the focus of their services or program.

#### program structure

The organizational chart reflects where the program is in terms of administration and relationship to other programs and services of the organization.

#### · program goal statements

Perhaps one of the most important elements of all. These statements, if well thought out can significantly help a program determine what outcomes are really important, what can be measured and how. If not well-thought out, they are unusable, probably unmeasurable and will lead to a program that has no defined goals and one that will be unable to defend itself. Involving persons served and payers, as well as program staff in the development of goal statements will help reflect their values. Through related measures, persons served and payers will be able to determine if their expectations have been met.

#### admission criteria

The admission criteria detail characteristics, behaviors, disabilities, or other qualifications that a person must possess to be admitted to the program. Be very clear and specific in justifying these criteria. It will also then, serve to provide objective reasons for non-admission. Clear concise admissions criteria will assist third-part payers and other referral sources in directing clients to the most appropriate resource.

#### list of persons served

This list clarifies and justifies the nature of the persons whom the organization expects to benefit from services. This list should show a logical relationship between persons served and the program goal statements, and between persons served and admissions criteria.

#### list of services provided

This is a list of the services the program offers. It also lists the resources available for an individual to achieve his or her goals. There should be a logical relationship between services provided, persons served, and program goal statements.

#### · statement of objectives

This is a statement that reflects the specific <u>quantifiable</u> objectives to meet the program goals. The statement of objectives should clearly express the desired changes expected <u>following</u> the provision of service.

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#### measures

Measures are methods an organization uses to indicate progress toward objectives. They should include efficiency measures, effectiveness measures, and measures of customer satisfaction.

#### time of application of measures

Time of application refers to when measurement takes place, such as at discharge, one week later, etc.

#### to whom measures will be applied

This specifies clearly who will be measured. In most evaluation systems all measures are not applied to all patients. An example would be: all clients returning to work after traumatic injury.

#### person served descriptors

Person served descriptors define the persons the program is serving in terms of severity of problem or barriers to success. An example would be: percentage of persons served with traumatic brain injury; percentage of persons served who are ventilator-dependent.

#### performance expectancies

This reflects the degree to which a program expects to achieve an objective. An example would be: Measure persons returning to work after discharge, Expectancy 75%; Actual result 82%. Performance expectancies should also be tracking costs, both expected and actual. This type of comparison of expectancies and actual outcomes provides a range of expectancies and helps put actual results in perspective, providing the organization with data by which to judge the program.

#### statement of the relative importance of objectives

All objectives must be weighted, as they are not all equally important. A weighted system should be designed to give greater weight to objectives that contribute to the overall program goals. (Wilkerson, in-press; MacDonell, Wilkerson, Acquaviva 1996; CARF, 1995)

A well-planned and implemented program evaluation system that includes these basic elements will answer six very important questions. These are:

- 1. Have we set the right goals? (goals, objectives and measures consistent with program mission)
- Are we reaching the goals we have set? (goals are measurable, performance is measured, 2. performance to goal comparisons are tracked)
- How valuable is our program? (the comparison of effectiveness to efficiency, to consumer 3. satisfaction)
- Are consumers satisfied? (Satisfaction with services provided; degree to which consumer 4.



- was involved in planning, etc.)
- 5. Where do we need to improve? (tracking performance against goals or targets, reviewing and utilizing data for continuous quality improvement, CQI)
- 6. How do we compare? (The programs effectiveness and efficiency in comparison to other programs). (Wilkerson, in-press;)

#### Conclusion

In these days of cost cutting by facilities and reductions in payments for services, a well-planned program evaluation system can provide solid information for organization wide decision making. It is also increasingly important to consumers, payers and providers to know how a programs effectiveness and efficiency compare to other programs. As we begin to develop program evaluation systems for Assistive Technology we need to focus on ways to make the information we collect useful to all stakeholders and look for ways to utilize the information to enhance quality of services.



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# CHARACTERISTICS OF A MEANINGFUL OUTCOME ASSESSMENT

Marcia J. Scherer, Ph.D.

In a 1992 Rehab Brief, the National Institute on Disability and Rehabilitation Research (NIDRR) summarized the fundamental role of measurement, assessment, and evaluation in rehabilitation as follows:

Consumers are measured to establish their eligibility for benefits or services, to determine which services are appropriate, to assess their needs, to ascertain their current level of functioning, and to estimate their potential (NIDRR, 1992, p.1).

Regarding outcomes measurement, the goal is to measure and document the effectiveness of AT as an intervention. In other words, to show that AT does, indeed, make a difference for those who use AT.

The development of any outcome assessment instrument or measure requires field testing and careful analyses of the results before use can be expanded. Before purchasing or using an outcome assessment instrument, it is a good idea to make sure it has gone through a rigorous process of development and validation and that a manual exists to guide you through its correct use, interpretation, etc. The traditional approach to instrument development and validation is as follows:

#### 1. Domain definition

The behaviors and traits of measurement interest will be identified. For example, is the measurement interest in global physical functioning or on something more specific such as mobility. Identified traits and behaviors will form an item pool of potential questions to include in the assessment instruments.

#### 2. Content validation

A pool of items are generated and each is judged by its

\* clarity

#### \* importance

Then acceptable items are assembled into a pilot version of the measure.

#### 3. One-to-one administration

The items will be administered to a few individuals representative of the population for whom the instruments are intended. Draft instruments will be distributed after obtaining



informed consent from all participants. After participants in the one-to-one administration have completed the draft instruments, items will be discussed with each individual to check for any problems with wording, cultural insensitivity, directions, or level of difficulty. Based on the results of the one-to-one administration, revisions to the instruments and their administration will be made.

#### 4. Field testing and analyses

Larger numbers of individuals will participate in the process and complete the assessment instruments. Item analyses will be performed as will factor analyses on the instruments' subscales when a sufficient sample of responses has been obtained. Item analyses will measure item difficulty and variability and an estimate of the reliability of the instrument. The mean and standard deviation of the item traditionally estimate item difficulty and variability. A common method of determining the item's discrimination is to correlate the item with the total score. This correlation is called an item-total correlation. Factor analyses on the subscales will be viewed as indicative rather than definitive when working with small samples.

#### 5. Revisions

Items will be retained, modified, or deleted based on the results of the item analyses. It may take several years before a final version of an assessment instrument is ready for wider distribution.

#### 6. Measure validation

To be considered a quality measure, an assessment instrument should provide evidence of its validity and reliability.

VALIDITY refers to the extent to which an assessment instrument measures what it purports to measure. It is an indication of the instrument's usefulness and appropriateness. A measure may be valid for use in one setting or with one population, but not others. There are several different kinds of validity, examples of which are listed below.

**CONTENT VALIDITY** is the extent to which an instrument's items derive meaningful information according to judgments by experts (professionals in the field, expert users, etc.). When experts read the items and judge that each one taps into a meaningful area, it is said that the measure has face validity.

CRITERION-REFERENCED VALIDITY is not based on expert opinion, but rather how well it measures a particular outcome.

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**CONCURRENT VALIDITY** focuses on a sample of behavior as indicative of actual behavior (e.g., how far one can walk in the clinic is the same as how far one can walk at home) or how well a measure correlates with other similar measures.

**PREDICTIVE VALIDITY** is concerned with forecasting a future behavior (e.g. FIM scores predicting hours of required assistance). One type of validity that deserves more attention in our field is consequential validity, or the degree to which the results are used in a manner beneficial to the system, profession or field.

**CONSTRUCT VALIDITY** is the degree to which an assessment instrument measures its underlying theoretical construct. For example, IQ is a theoretical construct that is not directly observable, so IQ tests were designed to try and quantify (or measure) it. Convergent validity is concerned with how well the results are correlated with other indicators of the same behavior e.g., other IQ test results).

**DISCRIMINANT VALIDITY** addresses how well the measure remains uncontaminated by variables unrelated to the behaviors of interest. For example, if you want to assess the capacity for independent ambulation, items that really assess energy level or fatigue need to be examined for retention.

**SCREENING MEASURES** try to approximate more comprehensive clinical evaluations or professional judgments. Their validity is assessed according to how well they accurately pick up those individuals with the condition and also how well they screen out those who do not have the condition. (See Figure 1).

**RELIABILITY** of measures is concerned with "reproducability" of results or the degree to which a measure yields the same results when administered across different points in time (test-retest reliability) or by different raters (inter-rater reliability)

#### 7. Finalization of instruments and process

Instruments are traditionally considered final versions when all field and pilot testing is completed and reliable and valid instruments exist with a sufficient number (minimum number for "minimum data sets") of quality items. In the field of rehabilitation, however, finalization involves ensuring accessible formats and the accommodation of persons regardless of age, gender, race, national origin, color, or disability.



#### FIGURE I VALIDITY OF SCREENING TESTS

**SENSITIVITY** 

Correct Identification of those with

(hearing loss)

A sensitivity of 94% =94/100 of the test administrations showed hearing loss in persons with hearing loss

6/100 of the test admnistrations identified hearing loss in persons without loss

**SPECIFICITY** 

Saying someone does not have a (hearing loss) when in fact, they don't

A specificity of 72% =72/100 of the test administrations indicated no hearing loss in persons with no loss

28/100 of the test administrations indicated no hearing loss for persons with loss

#### TO CALCULATE THE SENSITIVITY AND SPECIFICITY OF A SCREENING TEST:

1. Set up a 2x2 table as follows:

#### Condition

		Present Absent Total		
test result	Positive	50	15	65
	Negative	10	405	415
ī	Total	60	420	480

- 2. Sensitivity =  $50/60 \times 100 = 83.3\%$
- 3. Specificity =  $405/420 \times 100 = 96.4\%$
- 4. Percent of false positives =  $15/420 \times 100 = 3.6\%$
- 5. Percent of false negatives =  $10/60 \times 100 = 16.7\%$
- 6. Prevalence of condition =  $60/480 \times 100 = 12.5\%$
- 7. Predictive value of a positive test =  $50/65 \times 100 = 76.9\%$
- 8. Predictive value of a negative test =  $405/415 \times 100 = 97.6\%$
- c. M. J. Scherer 2/13/90



#### SELECTING AND USING MEASURES REVIEWED IN THIS BOOK

Obtaining the most useful information for AT decision-making requires a combination of consumer observations and input, subjective professional judgment, and objective measurement. When you decide to use a measure for assessing a particular domain, it is often helpful to have some guidance in asking the most appropriate questions and addressing key assessment or measurement issues.

The following has been adapted from the book, "Psychological Assessment in Medical Rehabilitation" (Cushman & Scherer, 1995) for the purposes of outcomes measurement in AT.

#### I. Determine the Information Needed/Desired

There are many measures reviewed in this book. Where do you begin in selecting among them? The following are some key questions to ask at the beginning of the assessment process:

- 1. What is already known about the domain(s) of interest?
- 2. Who can best provide the desired data?
- 3. Whose perspective is it important to obtain?
- 4. What is important to find out now in these areas to best help the individual and guide AT decisions?
- 5. What will be important to know for later AT decisions?
  Regarding the use of measures for outcomes assessment, examples of key questions to consider are:
- 1. Who wants to know information on outcome achievement?
- 2. What is expected/acceptable as evidence of outcome achievement? From whose perspective?

## II. Specify what is to be Measured

The assessment of core capacities, functioning/performance, and outcome require different measures as indicated by the variety of measures reviewed in this book. Depending on the focus at a particular point in time, it may be less important to measure, for example, ambulation than muscle tone. Examples of key questions to consider are:

- 1. What information is wanted from a measure?
- 2. Is the desired information specific or general?
- 3. Given the information needed/desired, which measure(s) in this book addresses the area(s) in need of assessment?
- 4. Can the desired information be measured accurately and with precision?



5. Will measurement yield better information than professional judgment?

# III. Identify what Exists to Systematically Collect the Desired Information/Data

Once the assessment goal is established, this book reviews a variety of measures some of which are very specific, some global; some are unidimensional, others multidimensional. Some require considerable time to administer, others are brief and can be completed in a few minutes. Some require paper-and-pencil, others a computer. Knowing what information is desired and weighing that against the available time and resources to obtain it will help narrow the possibilities.

It is becoming increasingly common to turn to brief, abbreviated, measures in order to save time and costs. The use of brief measures for the assessment of complex problems and for reaching complex treatment/rehabilitation/ outcome decisions has frequently left important information gaps. The results may not consider consumer background, ethnic/cultural and gender differences, etc. which can affect the validity or meaningfulness of the results regarding that individual. Some measures, however, assess a selected minimum number of behavioral indicators to be determined "sufficient." Thus, there are trade-offs to be weighed between the use of abbreviated and long versions of measures.

Examples of key questions to consider are:

- 1. Is a measure the best way to obtain the information needed/desired?
- 2. Do you want/need to construct your own measure? If so, the procedures and ethics of instrument development need to be consulted.
- 3. Which measure described in this book seems the most applicable for this individual?
- 4. Is a global form most appropriate, or one with subscales?
- 5. Is there an abbreviated version? What information is sacrificed by using it?
- 6. What resources are required to use this measure (cost of materials, time to administer and score, computer use, etc.)?
- 7. Are qualified personnel available to administer, score and interpret the results of the measure?

#### IV. Determine who Needs to be Involved

Beyond the involvement of the consumer, it may be useful to assess family members and significant others as they may be the ones the consumer needs to rely upon to maintain rehabilitation outcomes. Persons with disabilities often require help in completing measures. They may need to have questions read to them and/or have someone fill in the answer sheet. There may need to be a sign language or other language translator present. The selection of an assistant needs



to be made carefully in order to obtain honest answers on the measure. Examples of key questions to consider are:

- 1. Who can best provide the information needed/desired?
- 2. Does the respondent need another person to assist him or her?
- 3. Will the assistant interfere in any way with the collection of accurate information?

#### V. Select Measures/Obtain Informed Consent

The selection of an assessment instrument requires attention to its psychometric properties and a weighing of the risks and benefits to the consumer. "Informed consent" is defined in the 1985 Standards for Educational and Psychological Testing (presently under revision). It is important to realize that the broader the domain assessed, (from ambulation to ratings of social behavior) there will be increasing losses of clarity and specificity. Acceptable levels of subjectivity should be considered. Examples of key questions to consider are:

- 1. Does the instrument describe, screen, predict or evaluate?
- 2. What are the populations to which this measure applies?
- 3. Is the reported psychometric evidence adequate?
- 4. Will the measure yield useful information regarding this individual and AT?
- 5. What are its limitations?
- 6. Does it have utility in an outcome-based health care system?
- 7. Does it meet the Standards of the Code of Fair Testing Practices?
- 8. Are the methods and means of obtaining scores/profiles worth the time and expense to get them?
- 9. What are the risks and benefits to the individual?
- 10. Are qualified persons available to administer, score and interpret the results?

# VI. Administer Measure(s)/Consider Adaptations, Modifications, Accommodations

It is often necessary to make modifications and adaptations in measures and assessment situations to accommodate individuals in rehabilitation settings. Limitations in attention span, memory and other cognitive functions as well as the capabilities to hold a pencil, use a keyboard, or see print may require adjustments in the assessment process. Examples of accommodations for persons with hearing loss are the use of sign language interpreters and more graphic assessment measures. Persons with vision loss can benefit from large print, braille or audiocassette versions of instruments. Individuals with motor impairments may require such accommodations as



computerized assessment or the recording of responses by an assistant. Suffice it to say here that AT specialists must be a model for all other professions in accommodating the specialized needs of individuals with disabilities in all assessment situations. AT needs to also be a role model for the involvement of consumers in the assessment process.

Nearly all assessment today occurs in a multicultural context, also necessitating adaptations in measures and assessment. Yet, cultural loadings (the effects of cultural experience) can be either desirable or undesirable depending on the construct being assessed, the context, and the inferences to be drawn. The assessment of individuals from culturally diverse populations should include only measures that are culturally and racially bias-free and which attend to such cultural sensitivities as variations in definitions of terms, views of confidentiality, and cultural differences toward self-disclosure. The language used in the measure should be understandable to the individual with any culturally offensive or controversial material removed. If the measure selected is not available in the language of the particular consumer, another measure will need to be administered or the results are apt to be meaningless, or worse, misleading when either false positive or false negative results are obtained. Other issues regarding the assessment of persons from diverse cultural populations are discussed in Guidelines for Providers of Psychological Services to Ethnic, Linguistic, and Culturally Diverse Populations (APA Office of Ethnic Minority Affairs, 1993). Examples of key questions to consider are:

- 1. Will the individual understand all the words and phrases in the measure's items and not be offended by any of them?
- 2. Do accommodations need to be made in the measure or assessment process to get accurate, unbiased, and meaningful results?
- 3. Will the individual interpret items in the way intended by the developers of the measure and by providers?

#### VII. Score Measures

Scoring can be time-consuming and expensive. If hand scored, the process can be slow; computer scoring requires access to a computer or the requisite funds to pay to have it scored. It is often more efficient to train support personnel to score the more straightforward measures. Examples of key questions to consider are:

- 1. Do the necessary resources exist to properly score the instrument?
- 2. Who will get the results?
- 3. Which is the best way of presenting the results for those who will see them?



#### VIII. Analyze and Interpret Results

The purpose of most measures is to focus on and uncover problems.

Examples of key questions to consider are:

- 1. Are there undue factors which may have influenced the results (for example, the medication the individual was on at the time the measure was administered)?
- 2. Is the norm group appropriate and relevant?
- 3. Do the results make intuitive sense and fit with your professional judgment/assessment?
- 4. Have all the steps been taken to ensure that the most valid inferences can be drawn?

#### IX. Select AT(s) and Document Rationale

The broad purpose of assessment in AT is to assist in the derivation of devices and other interventions to enhance a person's functioning and ultimate quality of life. The assessment process should reveal obstacles to improved functioning and point the way to areas in need of further exploration. It is important to monitor individuals' progress and repeat measures/assessments during treatment. When this is done, then it is possible to document outcome attainment. Examples of key questions to consider are:

- 1. Has assessment data been balanced with good professional judgment and interpretation and has unfounded personal opinion been minimized?
- 2. Has the data been used to guide the decision-making of all the appropriate individuals on the AT/rehabilitation team, including the consumer?

#### In Summary...

This was just a very brief overview of the considerations involved in the development, validation, selection, and use of measures and outcome assessment in AT. Specialized resources exist on each of the above topics. Below are some readings relevant to our field that do not presume an advanced background in statistics and research methods.

#### FOR FURTHER READING...

American Educational Research Association, American Psychological Association, National Council on Measurement in Education. (1988). Code of fair testing practices in education. Washington, DC: American Psychological Association.



American Educational Research Association, American Psychological Association, National Council on Measurement in Education. (1985). Standards for educational and psychological testing. Washington, DC: American Psychological Association.

American Psychological Association. (1986). Guidelines for computer-based tests and interpretations. Washington, DC: Author.

American Psychological Association Science Directorate. (1991). Finding information on psychological tests. Washington, DC: Author.

American Psychological Association Science Directorate. (1991). Finding unpublished psychological tests and measures. Washington, DC: Author.

APA Office of Ethnic Minority Affairs. (1993). Guidelines for providers of psychological services to ethnic, linguistic, and culturally diverse populations. American Psychologist, 48, 45-48.

Cushman, L.A. & Scherer, M.J. (Eds.). (1995). Psychological Assessment in Medical Rehabilitation. Washington, DC: APA Books.

Dittmar, S.S. & Gresham, G.E. (1997). Functional Assessment and Outcome Measures for the Rehabilitation Health Professional. Gaithersburg, MD: Aspen.

ERIC Clearinghouse on Assessment and Evaluation, The Catholic University of America, Department of Education, Washington, DC 20064.

Johnston, M.V., Keith, R.A., Hinderer, S.R. (1992, December). Measurement standards for interdisciplinary medical rehabilitation. Archives of Physical Medicine and Rehabilitation, Special Education Issue. 73(12-S).

Joint Committee on the Standards for Educational and Psychological Testing. (1994, October 7-9). Open Conference on the Revision of the Standards: Oral Testimony Summaries; Summary of Panel Discussions. Author.

National Institute on Disability and Rehabilitation Research.(1992). Human measurement in rehabilitation. Rehab Brief, 14(2), author.

In addition to the producers of the above publications, organizations to contact for publications of direct relevance to this topic include (a) CARF: The Rehabilitation Accreditation Commission, (b) the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and (c) The National Center for Outcomes Research, a program of the Council on Quality and Leadership in Supports for People with Disabilities.



# WHERE ARE WE HEADED WITH ASSISTIVE TECHNOLOGY OUTCOMES?

#### Roger O. Smith, Ph.D., OT, FAOTA Marcia J. Scherer, Ph.D.

Dr. Frank DeRuyter noted in his section, "Concepts and Rationale for Accountability in Assistive Technology" that, "Accountability today will minimize the denial of goods and services tomorrow." It was our guiding premise in assembling these volumes that accountability can be achieved by measuring the changes, or outcomes, that result when we provide assistive technologies to consumers. Furthermore, we believe that the greatest threat to consumers' access to AT is payors' lack of knowledge about AT outcomes. For years those familiar with assistive technology have seen the positive results of assistive technology applications. In fact, the impact of assistive technology has seemed so obvious to the field that those closest to assistive technology intervention have taken outcome for granted. The coming of the new millennium must change this contentedness.

While the need to measure outcomes of AT is becoming more evident, the means of doing so are not always apparent or easy. In fact, both the National Institute on Disability and Rehabilitation Research (1995) and the Center for Medical Rehabilitation and Research of the National Institutes of Health (1993) have determined that outcomes measurement regarding AT is an important research need. Statements from these two agencies clearly call for the 1) enhanced use of outcomes measurement systems in practice and 2) the development, testing, and improvement of methods for measuring the outcomes of interventions for people with disabilities.

The application of assistive technology outcomes assessments and outcomes research have their own methodological challenges. On one hand, assistive technology outcomes are straightforward. Assistive technology, afterall, is tangible and the results seem to be overt. This is somewhat deceptive, however. Measuring the impact of assistive technology has its own measurement limitations. While some limitations are common to any habilitation or rehabilitation intervention, some are specific to assistive technology.

# **Issues in the Measurement of AT Outcomes**

The Proof is in the Pudding: Validity

Successfully documenting outcomes depends on having available appropriate measurement



instruments and methodologies. The examples of instruments in Volume 2 can be considered to be representative, but certainly not exhaustive. Undoubtedly, there are quality measures being used in the field of which we were not made aware. Additionally, new instrumentation and approaches to measures will be created (or older measures radically adapted for assistive technology applications). But even a cursory review of the measures in Volume 2 reveals that existing instruments tend to be very focused in a given practice area of assistive technology or are limited to a particular functional domain. In fact, as we delve deeper into the topic of assistive technology outcomes measurement we find that it is very complex. While many assistive technology devices show a clear and demonstrable impact on the lives of the individuals who use the devices, quantifying this effect using a credible process is much more involved than one would think.

Take for example, construct validity. Construct validity is whether an instrument or an approach measures what it hopes to measure. If we measure the outcomes of assistive technology use, the question is, are we really measuring the relevant effects of the assistive technology intervention? Could the effects result from other related interventions?

While the overall concept of construct validity is simple, factors related to construct validity may be the most challenging aspect of developing sound assistive technology outcomes measures. Certainly other characteristics of assistive technology outcomes instrumentation are necessary, such as content validity and various types of measurement reliability. As the assistive technology field begins to tackle outcomes measurement, however, it is the construct issue which has plagued its early development. A discussion of the importance of construct validity follows as it affects developers when they create new measures and the practitioner when trying to select the most appropriate measure to use.

Fundamental questions must be asked such as," will the outcomes results provide a complete and accurate view of reality?" and "what kind of decisions may be made using the results of this outcomes information?" Might the results have an impact on the funding of particular types of programs or services? For example, if HCFA was to find that a cohort of stroke survivors used a walker for an average of a few weeks before improving to the point of discarding the device, they might authorize only rental payment and not purchase payment for Medicare recipients requiring this type of device. But for those stroke survivors who still require use of a walker and have their rental period expire, there may be important negative consequences for their health as well as mobility.

The results from outcomes measurement can also influence decisions made to commence, G Q



continue, modify, or discontinue services or programs. For example, if a health maintenance organization (HMO) were to find that basic self-care assistive technology devices as applied by one service program allowed individuals to return home from a hospital on the average of 1/2 day sooner and that they were happier doing this, the HMO could be encouraged to continue referrals to this particular rehabilitation program. But that decision would be based on just partial information about that program's functioning. Incomplete views of outcomes can also adversely impact future services offered to individual consumers as well as future research emphases.

#### Selecting the Outcomes to Measure

DeRuyter suggests that clinical, functional status, quality of life, satisfaction, and cost are all important. Smith supplements this categorization, stating that each area of outcome can be elicited obtaining objective or subjective data. The subjective data provide the rich perspective from the user of the assistive technology. Objective data, on the other hand, reveal how the assistive technology performs along more quantitative scales. Both are critical to understand the reality of outcome. For these reasons, it is likely that in the near future we will continue to need to cast a wide net with our assessments. With this comes the need to determine how many measures we need, how focused they need to be and, how fragmented the process becomes as a consequence. It appears that we will need many data collection approaches and must then integrate these diverse data into the most sensible package.

Several recommendations are made for today's practitioner about the selection of measures.

- 1. Stay abreast of the increasing number and types of outcome measures.
- 2. Consider the breadth and depth of the type of data you need.
- 3. Identify instruments which collect a variety of outcome data and from more than one perspective.
- 4. Plan on collecting data and in a consistent fashion.

We know two things: a) no outcome are documented without collecting data; b) data are worth more when they can be examined across time and users. Consistency is essential. In the future, as a field, we hope to identify core data collection instruments and approaches to maximize quality and consistency. Hopefully, these will be consolidated into larger databases, which will allow scrutiny into informative aspects of cost-benefit. Today, however, we need to begin by tending our specific outcome needs. Each individual area of practice needs to begin collecting data by finding the most relevant and best instruments available.



# Teasing Out the Impact of Assistive Technology from the Array of Interventions

Assistive technology is only one of many powerful approaches to assist people with disabilities. In addition to or instead of an AT, environments are accommodated, tasks adapted, or assistance is provided by another person (such as a personal assistant, spouse, or parent.) Most likely, combinations of all of these interventions are used in combination. Examining the outcomes of assistive technology in isolation is only possible by teasing it out from among the combination of possible interventions. Yet, there are often interaction effects between these different interventions called "parallel intervention" (DePape & Smith, 1987; Angelo & Smith, 1989; Smith 1991a). The interaction between intervention approaches may be so intertwined that the assistive technology cannot be implemented in isolation. If we are looking to design effective outcomes measures, we must tease out the specific assistive technology outcomes yet keep it in context with parallel interventions. Thus, when we examine the use of outcome instruments, we need to remain cognizant of the potential effects of other variables. The use of basic research principles that attempt to isolate and control variables will be valuable to substantiate the credibility of our outcome data.

#### The Variance in Population and Environments

Assistive technology is applicable to all age groups, individuals with all levels of impairment severity, and the full spectrum of etiologies. Moreover, assistive technology is applied across a multitude of situations in highly variable environmental contexts. While this seems a simple enough statement, the ramifications are somewhat onerous. On one hand, we desire a method of assessing assistive technology outcome that is consistent and efficient. Yet, no medical diagnosis, functional impairment or disability area, treatment, educational or residential setting, or type of assistive technology device is excluded. Almost 20,000 devices and combinations can be applied to individuals with all types of impairments, in virtually countless environments and situations. As an intervention, assistive technology poses as unique in the broad scope of its application.

Since measures must be specific, yet respect the context in which they are used, two implications for practice are clear: a) in all cases when we measure outcomes we need to carefully define which population and in which contexts we are measuring. Also, when we scrutinize outcomes data and interpret studies, the populations and contexts must be reported in context, b) large data-based research studies need to be mounted to examine trends, and identify the true



influence of environmental and individual variables.

#### The Measurement of Moving Targets

Outcomes are highly dependent on temporal factors. For example, how well an individual might use a manual wheelchair could depend on the activity he had been performing immediately prior to the outcomes testing situation. Outdoor weather, how tired the individual is, or natural recovery of a medical condition can have a major impact on momentary outcome. While these types of variables are easy to understand how they influence outcome, it is often not acknowledged how difficult the moving target phenomenon makes true measurement. These transient factors often seem so obvious that they are assumed as easy to control as in a formal laboratory research study. The problem is that they are much more difficult to control in naturalistic settings. This challenges any outcomes measurement system and highlights the importance of multiple data points over time.

Furthermore, the type of assistive technology that might be appropriate is also a moving target. One type of technology might be appropriate at a given point in time, but later the assistive technology may be obsolete for the individual and their particular needs. This is commonly seen in pediatric applications where individuals grow, develop and mature, or with communication devices for people with ALS where function slowly degenerates, but there are examples in almost all areas of assistive technology application. One might even say that assistive technology should be thought of as a temporary intervention. The length of time a given technology is appropriate becomes an important factor to measure.

# Towards Our Future and Beyond the Traditional to New Outcomes Measurement Strategies

Typical outcomes assessments throughout rehabilitation and other fields dealing with disability have created assessments where all individuals are evaluated with the same questions and comparisons made among persons. Indeed, it is only on this basis that traditional reliability and validity assessment has been performed in a normative way. In assistive technology, it has become increasingly apparent that due to the variance of people and their situations, standard questions may not elicit data important to an individual. Standard questions can skew the results so they do not accurately describe the individual's situation. AT outcomes measures of the future must accurately target relevant questions for the person and their unique needs. This may mean considering many innovative data collection methodologies which do not fit the mainstream of traditional test and



measurement theoretical foundations.

As another example where assistive technology may need to reach beyond traditional measurement theory, traditional scales have been dependent upon the objectivity of the data collected. The underlying theory is based on the concept that real data can only come from something observable. We know, however, that the usefulness of assistive technology is often best known by the user. Assistive technology assessment may be prudent to avoid constraining itself to objective quantitative methodologies.

Assessments related to the needs of people with disabilities, and data which are based on preferences or opinions, historically have carried little weight. It is difficult to add these numbers together or compare the numbers from one individual to another. However, we are seeing some innovation in this area. Within the last few years, a number of assessments have been published incorporating methods of soliciting subjective data in the form of preferences and opinion. For example, in The Matching Person and Technology (MPT) Model (Scherer, 1994) a person is compared to him or herself to assess change over time since personal preferences and needs are highly individualized. Then AT and other rehabilitation services can be tailored to meet a particular person's goals and desires and focus on what needs intervention, not who needs it. The MPT also has the capacity to obtain and compare data between users and providers, thus offering a means to take into account multiple subjective perspectives.

Other examples of innovations in AT outcomes measurement are the Trichotomous Tailored Sub-branching Scoring (TTSS) system used in OT FACT (Smith, 1992, 1995) and the user-centered assessment QUEST (Demers, Lambron, & Ska, 1996) which is based on the theoretical framework of the MPT.

Like AT itself, outcomes research is undergoing innovation. There are many players, yet practitioners are key to outcomes research. They are the primary data collectors and may need to devote some of their personal time to perform outcomes research if it is not supported by their organizations (Jutai, Ladak, Schuller, Naumann, & Wright, 1996). Faculty of professional educational programs must teach outcomes research methodology and expect

assistive technology graduates to understand how to read outcomes research and how to participate in the outcomes research process.

Certification and accreditation agencies must demand an understanding of outcomes measurement, theory and application for practitioners working in assistive technology and for the programs delivering these services. Researchers and developers performing basic research



pertaining to assistive technology must link their studies to functional outcome. Manufacturers and suppliers must be cognizant of outcomes studies and ethically promote devices to optimize outcomes as opposed to revenues. Assistive technology users must demand outcomes information as part of the process for selecting an assistive technology device or an assistive technology service. Agencies funding assistive technology services must support the additional expense of collecting outcomes data through the design and implementation of outcomes studies. Research funding agencies should emphasis the need for the development of innovative outcomes instrumentation and the testing and development of large database approaches.



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# ANNOTATED BIBLIOGRAPHY on ASSISTIVE TECHNOLOGY and OUTCOMES ASSESSMENT

#### INTRODUCTION

### Roger Smith, Ph.D., OT, FAOTA [Annotated Bibliography follows.]

Approximately forty papers were identified as key to current discussion of assistive technology outcome. While this search was not exhaustive, many of the topics which are relevant to assistive technology and outcome were identified, including some found in non-indexed sources (fugitive literature). Key articles representing the state-of-the-art in assistive technology outcome were annotated in this process.

This uncovered eleven articles pertaining to AT outcomes. Eight articles were found in the journal of Technology and Disability from its charter issue through 1997. RESNA annual conference proceedings were examined from 1982 through 1997 and located nine papers. Medline, CINAHL, Academic Search and ERIC were searched from 1982 to the present revealing nine articles to supplement those already found. Team Rehab Report and Rehab Management magazines also provided a couple articles. A few other papers were located using references lists within key articles as listed above or were identified within the network of practitioners and researchers focusing on outcomes in assistive technology.

This annotated bibliography provides a starting point for a review of outcomes in assistive technology. Several themes are easily seen from this brief review of the current literature. First, there is a paucity of outcomes research in assistive technology. While research is young in many of the rehabilitation-related fields, it is very apparent in assistive technology that outcome research and instrumentation is in its infancy. Most authors of the articles reviewed highlight the need for more outcomes research, outcomes data collection tools, and lament that more is not already done.

Second, articles related to assistive technology tended to fall into 6 categories: 1) Outcomes, 2) Matching the individual and the technology, 3) Quality of Life, 4) Abandonment, 5) Device Feature/ Performance, and 6) Cost. From these categories it is clear that the topic with the least coverage relates to the relative costs and benefits of assistive technology.



# ANNOTATED BIBLIOGRAPHY on ASSISTIVE TECHNOLOGY and OUTCOMES ASSESSMENT

### Prepared by Marlene Humbles, BS, OTR

Albaugh, P.R. & Fayne, H. (1996). The ETPA for predicting technology success with learning disabled students: lessons from a multimedia study. Technology and Disability, September, 313-318.

The study outlined in this paper was designed to test the validity of a modified version of the Educational Technology Predisposition Assessment (ETPA) as a tool to measure early adolescents' responses to CD-ROM technology with special focus on learning disabled students. The ETPA is a self-report form that rates the characteristics of the technology, the individual's temperament, and the environment in which the person will use the technology in four subscales. Results indicated that proper assessment of the students would enhance their ability to function in a multimedia environment.

Bain, B., Block, L. & Strehlow, A. (1996). Survey report on the assessment of individuals with spinal cord injuries for assistive technology. Technology and Disability, August, 289-294.

This article points out the current assessment process used by rehabilitation teams working with individuals with spinal cord injury in the area of assistive technology. The authors stress that three major factors need to be considered to provide individuals with the most appropriate devices: 1) the individual's highest level of functioning; 2) the tasks s/he desires to perform; and 3) the required level of functioning needed in order to perform those tasks. Various models of assessment were introduced that highlighted the different needs of the consumer, i.e., desire to return to work, predicted continued use of devices after discharge, more general model for variety of assessment needs, the device itself, and the environment in which the device will be used. All of the models shared a common emphasis in securing an assistive technology device and include l) the client using the device; 2) the task to be accomplished, 3) the device itself; and 4) the environment. The results suggested that in choosing an assistive technology device that clients and care providers should be included in every step of the process, clients should become advocates for inclusion in the assessment process and that clients should be given the opportunity to try various assistive technology devices before a final selection is made.

Barnicle, K. & Lavanchy, C. (1991). An interdisciplinary approach to product assessment. In Presperin, J.J. (Eds). Proceedings of the 14th annual conference. Technology for the nineties, 30-32, Washington, D.C.: RESNA Press.

The importance of having a multi-discipline approach in evaluating the best assistive technology for consumers is discussed in this paper. Additionally, the consequences of a good and poor match between assistive technology and the user are reviewed. The results emphasized a collaborative effort take place between the representatives from disciplines required to evaluate the assistive technology and the consumer.



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## Bell, P., & Hinojosa, J. (1995). Perception of the impact of assistive device on daily life of three individuals with quadriplegia. Assistive Technology, 7, 87-94.

A qualitative study addressing the perceptions of three men with spinal cord injuries and their use of assistive technology devices in their daily lives was the topic of this article. The results showed that the ability to use these devices in their daily activities had a profound impact on their quality of life. Emergent themes and "fit" between user and device were discussed.

## Bergen, A.F. (1996). The effect of the mobility assessment process on outcomes: a beginning effort. Technology and Disability, May, 17-23.

The author conducts a study on the effectiveness of outcome studies on services rendered by rehabilitation technology suppliers (RTS) of mobility equipment and demonstrate that outcome studies are needed to support the role of the RTS. Three questionnaires were mailed out at three times during the provision of the mobility equipment and results indicated that greater satisfaction resulted in the assessment process when the consumer was involved in the entire process of receiving assistive technology products and/or services.

## Brown, D. (1996). Personal implications of functional electrical stimulation standing for older adolescents with spinal cord injuries. Technology and Disability, September, 295-311.

This study investigates the usage of Functional Electrical Stimulation (FES)-augmented in the home environment and the effects it may have for increasing the independence of persons with Spinal Cord Injury (SCI). One of the basic issues in considering assistive technology devices for persons is the overall effect it has on the user. The purpose of this study was to uncover and verify the qualities of older adolescent users of FES standing systems and aspects that have the potential to add successful use. To investigate these variables, the Offer Self-Image Questionnaire-Revised, the Personal Independence Profile, the Craig Handicap Reporting Technique, and the Assistive Technology Device Predisposition Assessment tools were used to record the responses of four participants. The results showed higher levels of psychological self-sufficiency and physical autonomy, cited creative activities for device use reflecting the enabling power of the device in the attainment of increased independence, and users felt they could benefit from the use of the device. The comparisons are limited due to the small number of participants in study which may not generalize the findings to a larger population.

# Cushman, L.A., & Scherer, M.J. (1996). Measuring the relationship of assistive technology use, functional status over time, and consumer-therapists perceptions of ATs. Assistive Technology, 8, 103-109.

This article systematically examined the circumstances surrounding the abandonment of assistive technology devices. The authors addressed two consecutive studies and interpreted reasons for nonuse of assistive technology devices after a specific follow-up period. Results showed that there did not appear to be a straightforward relationship between functional improvement and continued use of adaptive devices after discharge, rather, that although functional improvement occurred in many of the cases, other reasons for nonuse are still operative. Additionally, the differing views of the consumers and the professionals providing the assistive technology services were discussed.



Demers, L., Weiss-Lambrou, R., & Ska, B. (1997). Quebec user evaluation of satisfaction with assistive technology (QUEST): A new outcome measure. In Sprigle, S. (Ed.) Let's tango: Partnering people and technologies. Proceedings of the RESNA '97 annual conference, pp.94-96. Arlington: RESNA.

This paper highlights an assessment tool that evaluators can use to determine satisfaction with assistive technology devices and services. The purpose is to provide an outcome measure that will reflect a consumer-responsive and client-centered approach that will ensure objective assessment of the effectiveness and efficiency of the assistive technology device and/or services.

## DeRuyter, F. (1995). Evaluating outcomes in assistive technology: do we understand the commitment? Assistive Technology, 7, 3-16.

The author points out in this article the critical need for accountability and responsibility as assistive technology providers. Rising to the challenge of change to accurately document the outcomes of assistive technology devices and services is one of the key issues reflected upon. The author further identifies the categories of what to evaluate and the factors influencing on how assistive technology devices and services will be measured.

DeRuyter, F. (1994). Assistive technology usage outcome: A preliminary report. In Binion, M. (Eds). Proceedings of the RESNA '94 annual conference. Tuning in to the 21st century through assistive technology. Listen to the music, 27, Arlington, VA: RESNA Press.

This article addresses a project that was developed to begin to examine the underlying elements of assistive technology devices and/or services that may contribute to the outcomes. The author stresses the importance of accountability at levels in which assistive technology is delivered.

## Dowler, D.L., Hirsh, A.E., Kittle, R.D., & Hendricks, D.J. (1996). Outcomes of reasonable accommodations in the workplace. Technology and Disability, 5, 345-354.

A study was conducted to determine if reasonable accommodations in the workplace were made in accordance with ADA and if they were perceived as being effective. A variety of disabling conditions was included in this study. The results indicated that the cost figures for these accommodations as reported by employers were consistent with accommodation cost information found in the literature.

# Fuhrer, M. (1997). Evaluating the outcomes of assistive technologies and related services: the roles of program management-oriented and rehabilitation science-oriented outcomes research.

Paper presented at the annual AAATE meeting in Thessalonaki. The author outlines two different approaches to outcomes research in assistive technology: program management-oriented and rehabilitation-oriented approaches. The two approaches are compared in terms of their aims, audiences' choice of outcome criteria, characteristic strategies, financial support, and information dissemination practices.

## Gitlin, L. (1996). Factors predicting assistive device use in the home by older people following rehabilitation. Journal of Aging and Health, November, 8 (4), 554-576.

The goal of this study was to examine the use of assistive technology devices for one particular group of elderly that were discharged from rehabilitation to their homes. Factors influencing device use in the home, characteristics of consistent device users and potential reasons for abandonment were discussed.



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## Gitlin, L. (1995). Why older people accept or reject assistive technology. Generations, 19(1), 41-46.

The author discusses in this paper the use and abandon use of assistive technology devices and services. Factors that influence assistive technology use/nonuse such as person-based, nature of the environment and characteristics surrounding the device itself were reviewed. Factors that predict use, the user's perspective, and reasoning for abandoning the devices were highlighted.

## Gitlin, L.N., Levine, R., & Geiger, C., (1993). Adaptive device use by older adults with mixed disabilities. Archives of Physical Medicine and Rehabilitation, 74, (2), 149-152.

Two descriptive pilot studies were conducted to further examine the use of assistive devices by older adults were addressed in paper. The first pilot study focused on device use by older adults discharged from rehabilitation. The findings from this first study indicated that strategies for performing self-care activities may differ in the home from those that were performed in the hospital. The second pilot study focused on home care therapists working with the elderly with disability. The findings from this study indicated that relatively little or no coordination between inpatient rehabilitation training approaches and home care training in adaptive devices existed. Three interrelated factors were discussed as to why decrease in device use occurred in these two studies.

## Gitlin, L., & Schemm, R. (1996). Maximizing assistive device use among older adults. Team Rehab Report, 7, (4), 25-28.

With the growing number of elderly patients, the need for assistive technology devices and services will increase. Reasons why older adults abandon assistive devices were discussed and potential solutions to decrease the abandonment rate given. Guidelines to help increase the rate of device use were reviewed with a list of helpful questions to ask.

# Gordon, W. A., Brown, M.M., & Raquarsson, K. (1982). Assessing the impact of technological innovations on the daily life of persons with disabilities. In Bowman, B.R. (Eds). Proceedings on the fifth annual conference on rehabilitation engineering, 8, Bethesda, MD: Rehabilitation Engineering Society of North America.

This article addresses the concern of the impact of technological innovations on the user. This study described the impact that environmental control units and their use or nonuse had on the daily activities performed by 20 high-level quadriplegics. Results showed that consumers who were provided sufficient information about the use of the units were more likely to purchase and continue to use the unit to increase their optimum functioning.

# Hammel, J. (1996). What's the outcome? Multiple variables complicate the measurement of assistive technology outcomes. Rehab Management: The Interdisciplinary Journal of Rehabilitation, February/March, 97-99.

This article addresses the need to find ways of measuring the effectiveness and efficiency of assistive technology systems. "An outcome can be defined as a natural result or consequence and should be measured over time". Consumers and payors both are interested in cost-effectiveness data and the impact of assistive technology and services have on the quality of life. Earlier studies have focused solely on the impairment or pathology level of impact of assistive technology, whereas the impact of assistive technology on the functional task performance and the cost trade-offs affiliated with the improved performance is just beginning to be studied. Issues that include the accounting for multiple uses of assistive technology, long-term impact, abandonment issues, and which instruments should be used when measuring assistive technology outcomes are



further addressed.

Heerkens, W.D., Briggs, J., & Weider, T.G. (1997). Using peer mentors to facilitate the match of person and technology. In Lawrence, D.L. (Eds). Let's tango: Partnering people and technologies. Proceedings of the RESNA '97 annual conference, pp. 484-486. Arlington, VA: RESNA Press.

This article addresses the successful outcomes achieved by persons who have been mentored prior to selecting an assistive technology device and/ or service. It details how the mentors effectively employ the Matching Person and Technology assessment along with other assessments that will empower individuals to make the best choice for their assistive technology needs.

Hoyer, E.A., & Brandt, W.D. (1983). Devices to aid in independent living. In Bowman, B.R., McNeal, D.R., & Monzingo, D.W. (Eds). Proceedings of the sixth annual conference on rehabilitation engineering, pp. 19-21. Bethesda, MD: Rehabilitation Engineering Society of North America.

The authors address the need to evaluate communication devices and ensure successful use of devices by including the user in the evaluative process. The ease of which the features could be used, the cost and service of the assistive technology devices are key in identifying compliance by the consumer.

Jutai, J., Ladak, N., Schuller, R., Naumann, S., & Wright, M. (1996). Outcomes measurement of assistive technologies: An institutional case study. Assistive Technology, 8, 110-120.

This paper examines the assistive technology use in the context of total rehabilitation and the institutional culture in which services are delivered. Examples of outcome priorities have been identified along with the tools and approaches used in the MacMillan site of the Bloorview MacMillan Centre. The outcomes associated with assistive technology included the purpose of the outcomes measurement, the definition of the outcomes and the ease of implementation. Case studies were presented.

Keefe, B., Scherer, M.J., & McKee, B.G. (1996). Mainepoint: Outcomes of teaching American sign language via distance learning. Technology and Disability, September, 319-326.

This study highlights the delivery of instruction through the use of multimedia technology of computers, televisions, VCRs, and cordless phones. Students participated in a research study to complete coursework in American Sign Language via distance learning. The characteristics of students who successfully completed the course were compared to students who did not successfully complete the course. The Tennessee Self Concept Scale, Learning Styles Inventory, Survey of Technology Use and Educational Technology Predisposition Assessment were utilized to determine the characteristics. The Survey of Technology Use and the Educational Predisposition Assessment had consistent results regarding the profile of the successful students and can therefore potentially replace the more expensive tests of the Tennessee Self Concept Scale and the Learning Styles Inventory.



## Kohn, J. G., LeBlanc, M., Mortola, P. (1994). Measuring quality and performance of assistive technology: Results of a prospective monitoring program. Assistive Technology, 6, 120-125.

In order to determine the satisfaction with an assistive technology device, a follow-up program is required to accurately reflect the outcome (i.e., satisfaction, device performance) the device may have on the individual. This paper investigated the effects a follow-up program would have on a population of 60 consumers from Lucille Salter Packard Children's Hospital at Stanford as well on a replication study. This program was instituted as a quality assurance tool in order to make changes in the assistive technology device services as needed. Results showed that the follow-up program was successful in documenting device user feedback and the outcome measures were helpful in determining satisfaction and device performance.

# Mann, W.C., Hurren, D., Tomita, M., & Charvat, B. (1996). Use of assistive devices for bathing by elderly who are not institutionalized. The Occupational Therapy Journal of Research, 16, (4), 261-286.

The authors developed a hierarchical model for use in prescribing bathing devices related to mobility and support. The problems experienced with their use, satisfaction or dissatisfaction with the bath device, and matching the best bath device to the user were noted. The overall importance of careful measurement and assessment of needs were emphasized.

# McGrath, P.J., Goodman, J. T., Cunningham, J., MacDonald, B.J., Nichols, T.A., & Unruh, A. (1985). Assistive devices: Utilization by children. Archives of Physical Medicine and Rehabilitation, 66, (7), 430-432.

The use of assistive technology devices by children was the subject of this study. It addresses the manner in which the devices were prescribed-from a variety of professionals and the purchase of the items from a variety of commercial vendors. Reasons for utilization were reviewed. The results revealed that a high percentage of devices prescribed were used a large percentage of the time and that satisfaction rate was high.

### Merbitz, C. (1996). Frequency measures of behavior for assistive technology and rehabilitation. Assistive Technology, 8, 121-130.

This paper reviews a new approach that uses natural science measures and a model (selectionism) from the field of Behavior Analysis to document the outcomes of assistive technology. This method of selectionism has been used successfully in the field of education and the benefits are noted in empirically defined measurable outcomes. It is also useful for measuring change during treatment. The author emphasizes further pilot studies to determine the efficacy and effectiveness of this method when determining the outcome of assistive technology and to further the success of implementation of these ideas.

## Minkel, J. (1996). Assistive technology and outcome measurement: Where do we begin? Technology and Disability, July, 285-288.

This article emphasizes the importance of what a single service provider can do to measure the actual results of assistive technology devices and services they are delivering. Dr. Frank DeRuyter (1995) describes five dimensions of outcome measurement that can be used with varying audiences: 1) clinical results, 2) functional status, 3) quality of life, 4) satisfaction, and 5) cost. The researcher can choose a dimension that is most important and relevant and measure the changes in that dimension after identifying the audience the outcome measure is targeted. A comparison of assistive technology devices to the measurement of changes in clinical results is



reviewed along with an analysis of different methods to achieve an accurate picture of consumer satisfaction with assistive technology is also discussed. The author points out that more than one dimension of satisfaction needs to be measured, such as changes in functional status and analysis of costs as well as consumer satisfaction as noted in completed surveys. The outcome measure is dependent on the vantage point of consumer, provider and/or payor and it is necessary to take these roles into consideration when measuring outcomes.

# Nordenskiold, U., Grimby, G., Hedberg, M., Wright, B., & Linacre, J. (1996). The structure of an instrument for assessing the effects of assistive devices and altered working methods in women with rheumatoid arthritis. Arthritis Care and Research, 9(5), 358-367.

The authors used a newly developed instrument, the Evaluation of Daily Activities Questionnaire (EDAQ) in order to analyze the effects of using assistive devices or altered working methods on a group of twenty-one women with rheumatoid arthritis. The results showed that the EDAQ can be a useful instrument in assessing the effectiveness that assistive devices have on the impact of daily activities.

### Oldridge, N. B. (1996). Outcomes measurement: Health-related quality of life. Assistive Technology, 8, 82-93.

This study addresses the need for the evaluation of use of assistive technology devices to the health-related quality of life for people with disabilities. There is increasing importance to include the patient perception of usefulness and satisfaction of devices as related to their quality of life. The proponents of assistive technology claim that these technologies "improve patient quality of life", however, have difficulty in providing objective, measurable methods to document these effects. The author points out that generic and specific health-related quality of life instruments exist and could be potentially useful when examining outcome measures of assistive technology devices.

### Oldridge, N.B. (1996). Outcomes measurement: Health state preferences and economic evaluation. Assistive Technology, 8, 94-102.

Accountability of effectiveness of assistive technology devices is addressed in this article. With the increasing concern for economic evaluation of health care technologies and the impact they have on the quality of life years gained, it is important to develop techniques that include the cost and consequences of assistive technology devices. The author points out that an economic evaluation will help assistive technologists in making the most informed decisions in use of alternative assistive technology options. Further, the examination of the relationships between the cost of their interventions and the effectiveness of their interventions need to be addressed and documented.

### Parette, H.P. (1996). Augmentative and alternative communication impact on families: trends and future directions. Journal of Special Education, 30(1), 77-99.

The issues surrounding the family concerns prior to the prescription of augmentative and alternative communication (AAC) for children with disabilities is reviewed in this paper. AAC abandonment pattern characterizations were discussed along with implementation of AAC across multiple contexts, maintenance of AAC equipment and future directions.

### Phillips, B., & Zhao, H. (1993). Predictors of assistive technology abandonment. Assistive Technology, 5, 36-45.

Reasons for technology abandonment were discussed in this article. The purpose of this study was to determine the reasons why the assistive technology users accept or reject the devices. The research focused on three areas of device abandonment that involve the users' personal



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characteristics and technology acceptance, device attributes consumers prefer, and device utilization surveys. The findings of this study suggested that services that involved the consumer input and accommodating their needs on a long-term basis would enhance consumer satisfaction and reduce abandonment of the device.

### Pritham, C.H. (1996). Guest editorial: Quality improvement process/outcomes research. Journal of Rehabilitation Research and Development, 33(3), vii-viii.

The author discusses the quality improvement process currently existing in the area of outcomes in the healthcare field. The emphasis is to include the patient and his/her family members first to determine the quality of services rendered, how services are rendered within the system and how the patient will eventually return to the community and state of wellness. Focusing on qualitative research to encompass the complex nature on how the person perceives the outcomes from healthcare services is stressed.

# Russel, M. (1993). Continuous quality improvement in assistive technology- Establishing, maintaining, measuring. In Binion, M. (Eds). Proceedings of the RESNA '93 annual conference. Engineering the ADA: from vision to reality with technology, 14-16, Washington, D.C.: RESNA Press.

This paper addresses the Continuous Quality Improvement (CQI) strategies that have taken root in rehabilitation programs and emphasizes he shift that assistive technology services must focus on in order to provide quality services/products. Measuring the outcomes of services/products issued, customer focus, and defining the service strategy are key issues discussed.

### Scherer, M.J. (1996). Outcomes of assistive technology use on quality of life. Disability and Rehabilitation, 18(9), 439-448.

A review of the use and abandonment of assistive technologies along with results of research studies on the use of assistive devices are discussed in this article. The author articulates the influences on technology abandonment and stresses the importance of considering the consumer's perspective when selecting an assistive device to enhance their quality of life. Further, additional areas that require more study are detailed with a special emphasis for researchers to encompass a more comprehensive view of assistive technology.

Scherer, M.J., & McKee, B.G. (1994). Assessing predispositions to technology use in special education: music education majors score with the "Survey on Technology Use". In Binion, M. (Eds). Proceedings of the RESNA '94 annual conference. Tuning in to the 21st century through assistive technology. Listen to the music, 194-196, Arlington, VA: RESNA Press.

The purpose of this article was to show that by matching the person with the correct technology using the Survey on Technology Use for students in music education, an accurate predisposition to technology is assessed. Students were able to identify an increased number of educational opportunities available to them as a result of this assessment.

### Smith, R. (1996). Measuring the outcomes of assistive technology: Challenge and innovation. Assistive Technology, 8(2), 71-81.

Successfully documenting the outcomes of assistive technology use is presented in this paper. Methods to collect outcome data and discussion of new measurement strategies for assistive technology along with research designs were reviewed. Contributions of implementation of outcome strategies were emphasized.



Smith, R.O. (1993). Assessing the impact of assistive technology using OT FACT Version 2.0. In Binion, M. (Eds). Proceedings of the RESNA '93 annual conference. Engineering the ADA: from vision to reality with technology, 186-188, Washington, D.C.: RESNA Press.

The author discusses an outcome instrument that would be useful in measuring the impact of assistive technology. OT FACT is described in detail and the potential for the theoretical elements of this perspective to be compatible with a discipline-free assistive technology philosophy is reviewed.

### Smith, R.O. (1996). Measuring the outcomes of assistive technology: Challenge and innovation. Assistive Technology, (8), 71-81.

This article describes the need for outcome measurement tools in assistive technology interventions and highlights the issues relevant to meet these needs. The author addresses five categories that appear to be common to discussions of outcomes data dimensions that include 1) Performance of interventions; 2) User performance; 3) Support environment resources and performance; 4) Cost; and 5) Combinations of outcomes data. The author also discusses the challenges that rise when trying to isolate the particular impact of assistive technology devices from all other possible interventions; the variance that exists in the populations and environments; the wide variance in assistive technology services; measurement of dynamic variables; the dependence of assistive technology on other areas of the profession; and the number of studies on usage of assistive technology devices that focus solely on the issue of compliance. The importance of outcomes research methodology along with outcomes measurement is stressed.

# Van der Loos, H.F. & Hammel, J. (1996). Engineering reasonable accommodation: the delivery and use of assistive technology in a vocational training program. Technology and Disability, 5, 371-382.

This paper addressed the use of assistive technology that would assist the needs and capabilities of the individual student with learning disabilities using a three-workstation classroom designed by the Vocational Training Facility (VTF). The study focused on the integration of the assistive technology into the workstation and the reasonable accommodations solutions offered to empower the consumer. The results showed that if a reasonable accommodation was done well and focused on empowering the consumer to help them make the best choice, which a successful impact on the entire process of integrating the assistive technology to the consumer was made.



#### Annotated Bibliography by Category

The following table sorts the annotated bibliography in the following categories: outcomes, matching person with technology, quality of life, abandonment, device feature/performance and cost.

#### **OUTCOMES**

Definition: The quality of both assistive technology services and devices is determined by measurement of outcomes resulting from both the provision of the services and devices and the utilization of the technologies to facilitate functional improvement and quality of life for the individual consumer. Outcome measures evaluate the end result of the assistive technology intervention (Cook & Hussey, 1995). The following articles addressed outcome measures issues:

Bergen, A.F.(1996) Demers, L., Weiss-Lambrou, R., & Ska, B. (1997) DeRuyter, F. (1995) Fuhrer, M. (1997) Hammel, J. (1996) Jutai, J., Ladak, N., Schuller, R., Naumann, S., & Wright, M. (1996) Keefe, B., Scherer, M.J., & McKee, B.G. (1996). Kohn, J.G., LeBlanc, M., & Mortola, P. (1994) Merbitz, C. (1996) Minkel, J. (1996) Oldridge, N.B. (1996) Oldridge, N.B. (1996) Pritham, C.H. (1996) Smith, R. (1996) Smith, R.O. (1993)

#### MATCHING PERSON WITH TECHNOLOGY

Definition: Involves the appropriate matching of person to technology. The three components of matching the person to the technology include the person who will be the user of the technology, the technology itself and the milieu or environment(s) in which the user interacts with the technology (Scherer, 1996). The following articles addressed matching person with technology issues:

Albaugh, P.R. & Fayne, H. (1996)
Bain, B., Block, L., & Strehlow, H. (1996)
Barnicle, K. & Lavanchy, C. (1991)
Heerkens, W.D., Briggs, J., & Weider, T.G. (1997)
Mann, W.C., Hurren, D. Tomita, M. & Charvat, B. (1996)
McGrath, P.J., Goodman, J.T., Cunningham, J., MacDonald, B.J., Nichols, T.A., & Unruh, A. (1985)
Scherer, M.J., & McKee, B.G. (1994)

#### **QUALITY OF LIFE**

Definition: Quality of life has been described as life satisfaction, well-being and general affect. It has been studied by looking at subjective reports along with such objective indicators as sociodemographic and medical factors, functional impairment, and ability to work. (Scherer, 1996).

The following articles addressed quality of life issues:

Bell, P. & Hinojosa, J. (1995) Brown, D. (1996) Scherer, M.J. (1996)

#### <u>ABANDONMENT</u>

Smith, R.O. (1996)

Definition: Device abandonment research falls into three important areas of study: users' personal characteristics and technology acceptance, device attributes consumers prefer, and device utilization surveys. (Phillips, & Zhao, 1993) The following articles addressed abandonment issues:

Cushman, L.A. & Scherer, M.J. (1996) Gitlin, L. (1996) Gitlin, L. (1995) Gitlin, L.N., Levine, R., & Geiger, C. (1993) Gordon, W.A., Brown, M.M., & Raquarsson, K. (1982) Parette, H.P. (1996) Phillips, B., & Zhao, H. (1993) Scherer, M.J. (1996)

#### DEVICE FEATURE/ PERFORMANCE

Definition: These are standards that specify how a device should perform and a set of tests to be used as a basis for comparing similar products from different manufacturers (Cook & Hussey, 1995). The following articles addressed device feature/performance issues:

Hoyer, E.A., & Brandt, W.D. (1983) Nordenskiold, U., Grimby, G., Hedberg, M., Wright, B., & Linacre, J. (1996) Russel, M. (1993) Van der Loos, H.F. & Hammel, J. (1996)

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#### COST

Definition: Involves labor cost and production costs. The following article addressed cost issue:

Dowler, D.L., Hirsh, A.E., Kittle, R.D., & Hendricks, D.J. (1996)



#### Citations for Definitions found in Table of Annotated Bibliography by Category

Quality of Life Category -- from Scherer, M.J. (1996). Outcomes of assistive technology use on quality of life. Disability and Rehabilitation, 18(9), page 441.

Matching Person with Technology Category -- from Scherer, M.J. (1996). Outcomes of assistive technology use on quality of life. Disability and Rehabilitation, 18(9). This definition was paraphrased from her definitions on pages 445-446.

Cost Category -- from Dowler, D.L., Hirsh, A.E., Kittle, R.D., & Hendricks, D.J. (1996). Outcomes for reasonable accommodations in the workplace. Technology and Disability, 5. This definition was paraphrased from the outcome - cost of accommodation on page 350.

Outcomes Category, Device Feature/Performance Category, and Abandonment Category from the Phillips and Zhao 1993 article.





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